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Lennisha Pinckney Date

EVALUATION OF THE GEORGIA HIV BEHAVIORAL SURVEILLANCE (GHBS) SYSTEM

BY

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Degree to be awarded: M.P.H.
Career MPH

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BY

Lennisha Lachelle Pinckney
M.P.H., Emory University, 2013
B.A., Spelman College, 2007

Thesis Committee Chair: Iris Smith, Ph.D., M.P.H

An abstract of
A Thesis submitted to the Faculty of the
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2013

Abstract

EVALUATION OF THE GEORGIA HIV BEHAVIORAL SURVEILLANCE (GHBS) SYSTEM

BY
Lennisha Lachelle Pinckney

Background: The National HIV Behavioral Surveillance (NHBS) system is an ongoing behavioral surveillance system that was established by the Center for Disease Control and Prevention (CDC) in 2003 to assess trends in HIV risk behaviors, testing, and HIV prevention services among three groups. The NHBS system is used primarily in cities where approximately 60% of all cases of acquired immunodeficiency syndrome (AIDS) had been reported. Atlanta, GA is on this list. This evaluation will assess the efficaciousness of the implementation of the Georgia HIV Behavioral Surveillance (GHBS) System.

Purpose: The purpose of this study is to conduct an evaluation of the Injection Drug Use (IDU) component of the GHBS project. This evaluation has been designed to collect information on the logistics of the GHBS project, to address relevant evaluation questions, and to conduct a thorough assessment of the performance of the GHBS project.

Methods: The study used a mixed method approach. Qualitative methods consisted of conducting key informant interviews with relevant stakeholders. Quantitative methods consisted of sending out an electronic anonymous survey to local HIV/AIDS organizations. Lastly, the CDC's framework for surveillance systems was used to determine if the GHBS system met specific standards.

Results: Results from the study showed that the GHBS system has been successful with reaching enrollment goals. However, there are some issues with dissemination of data, costs, and representation. It was discovered that staff of local HIV/AIDS organizations are aware of the GHBS system but a small percentage of the staff utilize the data.

Conclusions: Information collected from the key informant interviews and electronic survey shows that overall, the surveillance project is operating successfully. However, there are some areas of concern such as representativeness, cost, and dissemination of data that need to be addressed to improve the efficacy of the surveillance project.

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CHAPTER I

Introduction

The National HIV Behavioral Surveillance (NHBS) system is an ongoing behavioral surveillance system that was established by the Center for Disease Control and Prevention (CDC) in 2003 to assess trends in HIV risk behaviors, testing, and HIV prevention services among three groups. These three groups consist of Injection Drug User's (IDUs), Men who have sex with men (MSM), and heterosexuals. NHBS data are collected in rotating cycles, approximately once every three years from each of the three groups.

The NHBS system is used primarily in cities where approximately 60% of all cases of acquired immunodeficiency syndrome (AIDS) had been reported. Since HIV/AIDS rates are relatively high in Atlanta, Georgia with 66% of Georgians living with HIV/AIDS residing in the Atlanta Metropolitan Statistical Area (MSA), Atlanta was chosen to be one of the locations where a surveillance project would be conducted (HIV/AIDS Surveillance, Fact Sheet, 2011 health.state.ga.us). Three subgroups in the state of Georgia that are most at risk for HIV/AIDS infection are MSM, high risk heterosexuals, and IDU's. The Georgia HIV Behavioral Surveillance (GHBS) System which is conducted in the city of Atlanta focuses on data collection for these three subgroups. This evaluation project will focus on the IDU cycles previously conducted which are IDU cycle II and IDU cycle III.

The GHBS system uses a respondent-driven sampling (RDS) method, a type of peer driven chain-referral sampling to collect data (Heckathorn 1997, Broadhead et al, 1998). Approximately 7 to 10 IDU's are recruited by GHBS staff through referrals from local organizations and outreach. These individuals who are initially referred to the staff are known as seeds. GHBS staff anticipates that the seeds will come to the study site to participate in the survey and if the seed successfully completes the survey he/she is eligible to then recruit a specific number of other

IDU's to participate in the survey. This fosters a chain reaction in which recruiters and recruits continue waves of recruitment. Trained interviewers/staff members then administer a standardized survey for participants to complete. A handheld computer is used to conduct the survey. Additionally, the handheld computer is used to collect and store pertinent data. Participants are compensated for completing the survey and for agreeing to take an anonymous (optional) HIV test. The survey takes approximately 45 minutes to complete and the HIV testing takes about 10 to 15 minutes to complete.

Purpose of the Evaluation

The purpose of this thesis project will be to conduct an evaluation of the GHBS system. The evaluation project will determine if key components of the GHBS project are in place to yield results that will provide information to assess risk for HIV infection amongst IDU's and to plan better HIV prevention and treatment programs in their respective communities. This evaluation has been designed to collect information on the logistics of the GHBS project, to address relevant evaluation questions, and to conduct a thorough assessment of the performance of the GHBS project. The evaluation will be used in three strategic ways. First, the evaluation will determine the projects ability to provide information that can be used to accomplish its goals and objectives. Secondly, the evaluation will determine the level of performance of the GHBS project. Lastly, the evaluation will assess the usefulness of the data collected.

Evaluation Questions

Questions for this evaluation are concerned with the GHBS project's inputs, activities, outputs, and outcomes. More specifically, evaluation questions will address key components of the project.

1.) What challenges has GHBS staff encountered concerning the implementation of the GHBS project?

2.) Is the project achieving the goals that have been set forth by the staff and if so, what factors have contributed to the achievement of the goals set forth by GHBS staff?

3.) Were appropriate statistical tests or descriptive measures used when conducting an analysis of data?

4.) Is GHBS information being disseminated to its intended audience (data end users)?

5.) Is GHBS data being used by its data end users?

Stakeholders

Evaluation is stakeholder-driven. Thus, it is important to involve stakeholders in the process of evaluation.

<u>GHBS Staff</u>

GHBS staff has a vested interest in ensuring that operations of the project are properly in place. Effective implementation of the GHBS projects determines its overall success and this success determines the eligibility for future funding. GHBS staff consists of a project manager, project coordinator, program consultant, research interviewers, and interns.

<u>Injection Drug User's (IDUs)</u>

IDUs are the participants of the GHBS project. These individuals have a vital role concerning the success of the project because without their participation, data collection and recruitment goals would be unattainable.

CDC

The CDC provides funding for the GHBS project. The GHBS project manager reports the progression of the project to the CDC. Objectives and goals must be met to ensure that future funding is received for the GHBS project. The CDC seeks to provide information that is collected from the surveillance system in order to asses trends of HIV incidence, prevalence, and behavior.

HIV/AIDS Prevention and Treatment Programs

Once information gathered from the surveillance system is written and then published, this information can be disseminated to local HIV/AIDS organizations. HIV/AIDS organizations can use this information to improve their strategies for preventing and treating IDUs who are infected with the virus.

Logic Model

The logic model will serve as a guide for the evaluation of the GHBS project. Contents of the logic model consist of project inputs, activities, outputs, and outcomes.

Inputs

Inputs or resources are the human, financial, organizational, and community resources a project needs to implement the project (W.K. Kellogg Foundation, 2004). This portion of the logic model will display the resources available to the GHBS project to implement this project and to collect data relevant to the further development of the surveillance system.

Activities

Activities are the processes, tools, events, technology, and actions that are an intentional part of the projects implementation (W.K. Kellogg Foundation, 2004). GHBS activities will be implemented through the use of inputs (resources) and these activities will bring about the intended project modifications or results (W.K. Kellogg Foundation, 2004).

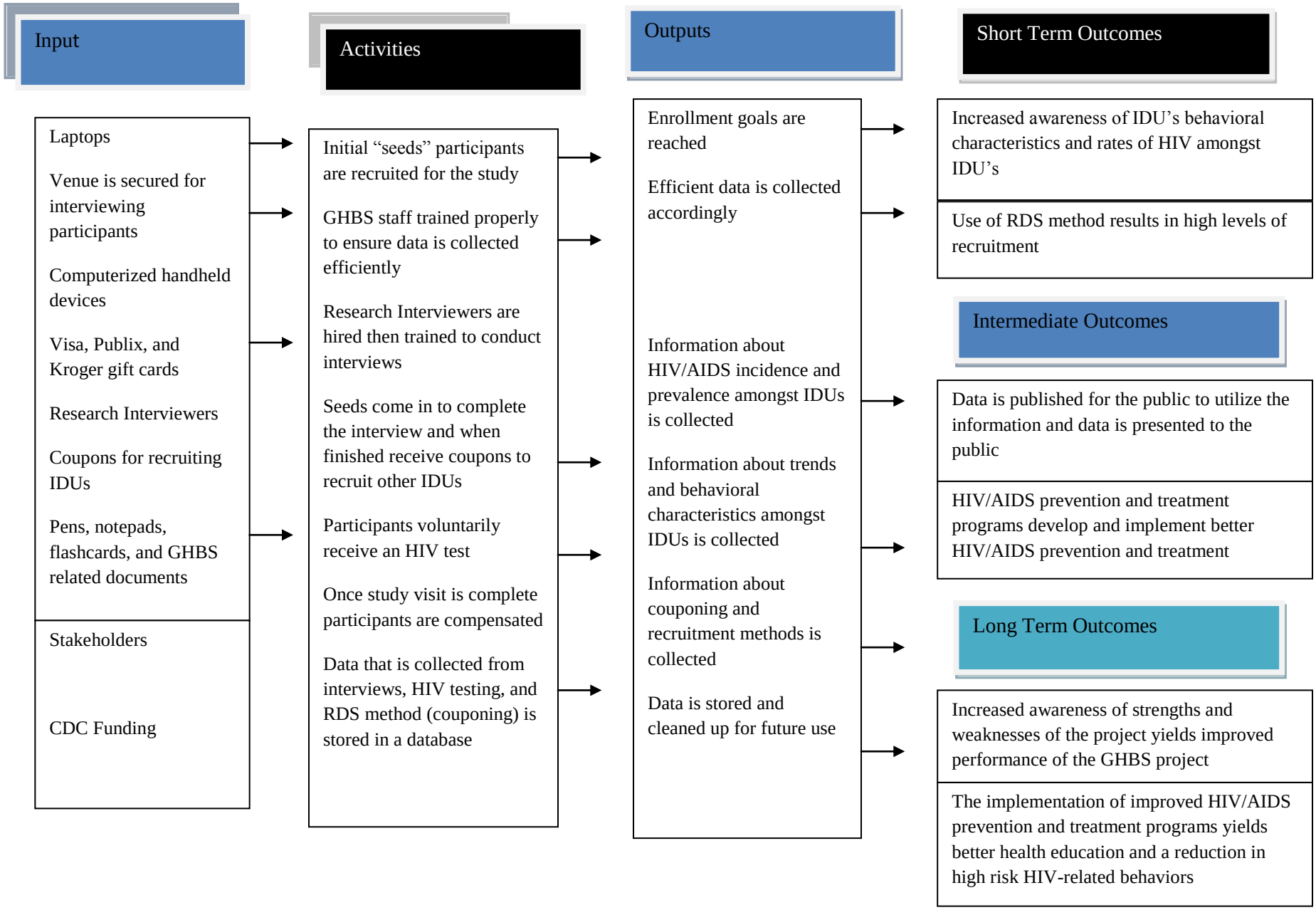
Outputs

Outputs are the direct products of the projects activities (W.K. Kellogg Foundation, 2004). Direct products of GHBS activities are inclusive of reaching enrollment goals and obtaining information about the trends and behavioral characteristics of IDUs.

Outcomes

Outcomes are the specific changes in the project participants' behavior, knowledge, skills, status and level of functioning (W.K. Kellogg Foundation, 2004). Short term outcomes for GHBS consist of providing reliable information about the trends and HIV rates of IDUs. Long term goals of GHBS consist of data end users being able to utilize this information to plan better HIV/AIDS treatment and prevention programs.

Figure 1- GHBS LOGIC MODEL



CHAPTER II-LITERATURE REVIEW

Introduction

This literature review will focus on the different facets of public health surveillance. First, the history and modernization of public health surveillance will be discussed. Next, details about HIV/AIDS surveillance in the United States will be discussed. Lastly, a comparison and contrast between the GHBS project and projects similar to the GHBS will be provided.

History of Public Health Surveillance

The initial concept of public health surveillance emerged approximately 6 centuries ago in Europe. Basic surveillance techniques began in Italy and were subsequently adopted in other countries. The utilization of morbidity and mortality data as a source for public health action arose in Europe with the emergence of scientific thought during the Renaissance, and subsequently spread to the Americas with the European settlers (Carter & Declich, 1994). The occurrence of the Black Plague in the fourteenth and fifteenth centuries led the Venetian Republic to appoint three guardians of public health to detect and exclude ships which had infected people aboard (Carter & Declich, 1994). Travelers from areas infected with the plague were quarantined in Marseilles and Venice to stop the spread of infectious disease. Records of vital events were preserved in numerous European towns beginning in the sixteenth century with the first London Bills of Mortality being developed in 1532 (Carter & Declich, 1994). During the seventeenth century, the parish clerks of London made weekly reports of the number of burials, with the causes of death to the Hall of the Parish Clerks' Company (Carter & Declich, 1994). Next, the clerk compiled statistics of deaths in London and other parishes and interpreted the statistical data to provide information about the plague. This information was disseminated to end users who could take public health action against the plague. It is during the eighteenth century that public health surveillance was perceived as an integral part of the provision of

public health (Carter & Declich, 1994). In 1766, Johann Peter Frank promoted public health surveillance in a comprehensive manner. Public health surveillance was a part of his Franks system of police in Germany and covered a wide range of public health issues which were inclusive of school health, injury prevention, maternal and child health, and public water and sewage treatment (Carter & Declich, 1994). Simultaneously, in the 1700's, Rhode Island (America) passed an act and law requiring the reporting of contagious disease, yellow fever, smallpox, and cholera. During the nineteenth century, surveillance involving the collection and interpretation of health-related data for the purpose of identifying appropriate actions became fully developed (Carter & Declich, 1994). William Farr, who is known as the founder of the modern concept of surveillance, became the first Compiler of Abstract (Carter & Declich, 1994). The twentieth century saw the expansion of the concept of surveillance and the development of many different surveillance systems (Carter & Declich, 1994).

Modernization of Public Health Surveillance

In the early 1980s, a concerted effort at CDC focused on the practice of surveillance, and in 1986, an internal report included the following revised definition of epidemiologic surveillance: The ongoing, systematic collection, analysis, and interpretation of health data essential to the planning, implementation, and evaluation of public health practice, closely integrated with the timely dissemination of these data to those who need to know (Thacker, Qualters, & Lee, 2012). The final link in the surveillance chain is the application of the data to prevention and control and includes a functional capacity for data collection, analysis, and dissemination linked to public health programs (Thacker, Qualters, & Lee, 2012).

The 1986 internal report was directed at CDC but also included information and recommendations i.e. a systematic approach for evaluating surveillance systems (Thacker,

Qualters, & Lee, 2012). A subsequent paper described the confusion engendered by use of the qualifying word "epidemiologic" to describe surveillance and argued for the use of the broader term "public health" instead (Thacker, Qualters, & Lee, 2012). The concern with the use of the word was that epidemiologic was more specific and marginalized while the term public health was more broad and applicable to other areas of the public health realm.

HIV/AIDS Surveillance in the United States

Since the initial cases of HIV/AIDS related diseases, one in particular that was common i.e. *Pneumocystis carinii (*pneumonia) were reported in the U.S., multiple data systems have been developed to monitor the trends of HIV/AIDS infection. This section will discuss the development and evolution of HIV/AIDS surveillance in the United States. Details concerning HIV/AIDS data systems will be highlighted as well in this section.

In 1981, soon after the first clusters of cases of *Pneumocystis carinii* pneumonia and Kaposi's sarcoma among gay men were reported, the Centers for Disease Control and Prevention (CDC), as well as state and local health departments, recognized that a new disease syndrome had made its appearance, and states began to collect case reports of AIDS (Nakashima & Fleming, 2003). These case reports were forwarded to the CDC and formed the basis for AIDS surveillance well before the causative agent, HIV, was identified in 1983 (Nakashima & Fleming, 2003).

As the public health effect of AIDS in the United States was recognized, the data collection systems to monitor various aspects of the disease evolved rapidly in number and complexity (Nakashima & Fleming, 2003). Early in the epidemic, gay men, many of whom were well educated and financially successful, organized into politically active groups that were instrumental in bringing public and government attention to AIDS and the interests of the

infected populations (Nakashima & Fleming, 2003). Thus, surveillance for HIV and AIDS in the United States has developed in an environment of controversy (Nakashima & Fleming, 2003). The national surveillance of HIV/AIDS and the populations at risk for HIV infection in the United States has been conducted by CDC in partnership with surveillance programs at the state and local levels (Nakashima & Fleming, 2003). CDC has a similar partnership with the Georgia Department of Public Health (GDPH) to implement the GHBS project. State and local health departments use active and passive surveillance methods to collect information on AIDS cases from multiple sources: reports from physicians and other clinicians, hospitals, clinics, laboratory reports, HIV counseling and testing sites, medical record reviews, and interviews with patients and providers (Nakashima & Fleming, 2003). Data are entered in state and local databases and forwarded to CDC electronically each month using software developed at CDC (Nakashima & Fleming, 2003). Personal identifiers are encoded, and records are encrypted before data are sent to the CDC; thus, CDC does not possess patient names or other personal identifiers (Nakashima & Fleming, 2003). Confidentiality of HIV/AIDS records is crucial to the success of HIV/AIDS surveillance.

Surveillance is undertaken using the following information systems and studies: the HIV/AIDS Reporting System (HARS), HIV seroprevalence and seroincidence studies, supplemental surveillance and evaluation studies, national mortality statistics, behavioral surveillance studies, and service delivery data systems (Nakashima & Fleming, 2003).

The government within each state has passed legislation, or written rules or regulations to mandate data collection on cases of AIDS within its jurisdiction. Such legislation was passed state by state during 1981–1986. By 1986, all 50 states, the District of Columbia and three US territories had instituted AIDS case reporting (Nakashima & Fleming, 2003).

Although laws and rules for reporting requirements in each state differ considerably, the Association of State and Territorial Health Officers (ASTHO) and the Council of State and Territorial Epidemiologists (CSTE) cooperate with CDC to set standards for consistency (e.g., standard case definitions), quality, and completeness of surveillance data on infectious diseases, including HIV and AIDS (Nakashima & Fleming, 2003).

The AIDS surveillance system has and will continue to undergo evaluation to ensure the high quality of the data and to ensure prevalence and trends in incidence seen is reliable (Nakashima & Fleming, 2003). Ensuring completeness of reporting, reducing duplication of cases, reducing delays in reporting of HIV/AIDS diagnoses, and ensuring accurate accounts of HIV/AIDS exposure will help to enhance the high quality of data and maintain reliable information.

CDC updates and publishes the *HIV/AIDS Surveillance Report* twice yearly and reports of HIV/AIDS trends are published in CDC publications, the *Morbidity and Mortality Weekly Report (MMWR),* in peer- reviewed scientific journals, and books (Nakashima & Fleming, 2003). Prevention program planners at all levels of government, researchers, the media, and others use the data (Nakashima & Fleming, 2003).

CDC provides funding and technical support to state and local health departments to collect and disseminate HIV/AIDS surveillance data through routine reports and feedback to reporting sources. Health departments use HIV/AIDS surveillance data to develop epidemiologic profiles and these profiles are used to allocate resources and prioritize interventions for prevention programs (Nakashima & Fleming, 2003).

Because HIV is spread primarily through sexual activity and drug use, surveillance of these behaviors has been recognized as an integral part of a comprehensive surveillance program (Nakashima & Fleming, 2003). Behavioral surveillance differs from traditional infectious disease

surveillance because interviews are usually required to obtain the desired information (Nakashima & Fleming, 2003). In addition, unlike surveillance of a disease for which laboratory tests can confirm the diagnosis, objective measures to validate the self-reported behaviors from interviews are more difficult to obtain (Nakashima & Fleming, 2003). Questionnaire design and the training of interviewers are critical to the accurate, unbiased measurement of behaviors. Instruments for collecting behavioral surveillance data range from brief and relatively simple to being highly detailed and complex (Nakashima & Fleming, 2003).

CDC's First Launch of a Surveillance Project Similar to GHBS

Prior to the launch of the NHBS system, the CDC launched another surveillance system that assessed trends of high risk populations. This surveillance project was implemented from 1993-1997. Data collection for IDU's was collected from 1993-1997. There were slight differences between the NHBS project and the serosurveillance project concerning the method for collecting data and the type of data that was collected. The serosurveillance project administered anonymous surveys where much of the information was collected from medical records and intake forms while the NHBS project administered anonymous surveys where all of the information was taken directly from the interview between the participant and the research interviewer. Another difference between the two projects was that the serosurveillance project collected information on low and high risk groups while the NHBS project solely collected information on high risk groups.

IDU's from the seroprevalance project were individuals who were entering drug treatment programs while the NHBS project collected information from participants via the use of the RDS method. NHBS wanted to collect data for the purpose of utilizing the data to implement better treatment and prevention programs. However, the anonymous serosurvey data have been used

for the following purposes: (1) to provide national and local estimates of the number of persons living with HIV infection; (2) to develop evidence to assist in making decisions on the allocation of resources for prevention activities through HIV prevention community planning; (3) to assist in projecting the number of people who may benefit from HIV-related care and treatment; and (4) to advocate HIV prevention activities such as voluntary testing and counseling services, treatment services, education, safe practices for health care workers, and applied public health research (HIV Prevalence Trends in Selected Populations in the United States: Results from National Serosurveillance, 1993–1997).

Although there were slight differences between the two projects, there were similarities as well. These similarities resulted in linkages between the activities and outcomes concerning the goals of both projects. Through the use of data collection (activities) both projects have obtained these desirable outcomes:

- Collected pertinent data that assessed trends of high risk groups.
- Provided information that can be used to implement better support programs for individuals infected with HIV/AIDS.
- Provided valid information about the rates of HIV amongst high risk populations.

Comparison of Similar Surveillance Projects

This section will focus on similarities between the GHBS project and a pilot study that was conducted in New York City. Similarities between the two projects consisted of:

- The use of the Respondent Driven Sampling (RDS) method
- Computerized techniques
- Eligibility screening methods

The pilot study's data collection began with eight seeds recruited from the Lower East Side syringe exchange program in which these seeds then recruited other drug users. This same

process of using seeds was the same method used by the GHBS project. The enrollment goal for both the pilot study and the GHBS project was 500.

The GHBS project uses a respondent driven sampling (RDS) process to recruit IDU's. This process has been shown to be an effective method for contracting this vulnerable "hard to reach" population. A pilot study was conducted in New York City to assess the effectiveness of RDS to recruit a large and diversified group of drug users in New York City (Abdul-Quader, Abu S. et al, 2006). RDS is based on the premise that peers are better able than outreach workers to locate and recruit other members of a hidden population (Abdul-Quader, Abu S. et al, 2006). RDS provides means for sample selection and evaluation of the reliability of the data obtained (Abdul-Quader, Abu S. et al, 2006). As such, it allows for inferences about the characteristics of the population from which the sample is drawn (Abdul-Quader, Abu S. et al, 2006). Unlike other chain referral methods, RDS allows for the assessment of relative inclusion probabilities for members of the population based on a mathematical model of the recruitment process (Abdul-Quader, Abu S. et al, 2006). This model is derived from a synthesis and extension of Markov chain theory and biased network theory and provides the bias for calculating both unbiased estimators and standard errors of confidence intervals (Abdul-Quader, Abu S. et al, 2006). The Markov chain theory is a process where values such as probabilities and discrete numbers are taken into a countable set. The biased network theory is a social theory that states that individuals have an influence on the behavior of those individuals for which they interact. These calculations are based on information collected from respondents regarding their relationship with both their recruiters and recruits and the size of their own social networks (Abdul-Quader, Abu S. et al, 2006). The statistical theory upon which RDS is based suggests that if peer recruitment proceeds through a sufficiently large number of waves, the composition of the

sample will stabilize, becoming independent of the seeds from which recruitment began and therby overcoming any bias the nonrandom choice of seeds may have introduced (Abdul-Quader, Abu S. et al, 2006).

The pilot study utilized a computer-assisted interviewer-administered personal interview (CAPI) device to interview participants. The GHBS project used a computerized device as well to conduct interviews. In addition to basic demographic information, the interview focused on drug and sexual risk behaviors, HIV testing history, exposure to HIV prevention services, and health status (Abdul-Quader, Abu S. et al, 2006). GHBS interviews focused on the same type of information.

The RDS process was used and resulted in this study exceeding its goal of 500 (within the 13 week timeframe). More specifically, using RDS, 618 DUs were recruited during 18 waves (Abdul-Quader, Abu S. et al, 2006). The eight seeds produced a total of 583 documented peer recruitments and 27 cases for which recruitment data was missing (Abdul-Quader, Abu S. et al, 2006).

Summary

Public health surveillance has evolved tremendously since its inception in Europe; it has become more modernized and is now a systematic tool that is used in other countries outside of Europe. In the mid 1980's, the United States made a conscious effort to define surveillance, determine the applicability of surveillance in the field of public health, and develop criteria for evaluating surveillance systems. HIV/AIDS surveillance became important when the first cases of AIDS related illnesses emerged. After these first cases of AIDS related illnesses were documented and HIV/AIDS was defined, cases of the diagnoses were captured. The collection of HIV/AIDS information has been ongoing since the early 1980's. The CDC launched a surveillance system

that was similar to GHBS however; this surveillance system is no longer active while the GHBS system is still ongoing. There are projects that are similar to the GHBS project; nonetheless, the GHBS system is the only surveillance project of its kind that collects information on the trends of HIV and behavioral characteristics of these three at risk groups.

CHAPTER III-METHODOLOGY

Introduction

This methodology section of the evaluation will focus on the evaluation questions and the data sources needed to answer these evaluation questions. Next, the procedures used for collecting information will be discussed. Additionally, the instruments used for data collection will be discussed. Lastly, the conceptual framework for the evaluation of surveillance systems will determine the credibility of the GHBS surveillance system.

Evaluation Design

The evaluation design will be based on a mixed methods approach. Both qualitative and quantitative methods will be used to address evaluation questions. The CDC's updated guidelines for evaluating surveillance systems will be used to determine the efficacy of the surveillance system.

The following five evaluation questions will be addressed:

1.) What challenges has GHBS staff encountered concerning the implementation of the GHBS project?

2.) Is the project achieving the goals that have been set forth by the staff and if so, what factors have contributed to the achievement of the goals set forth by GHBS staff?

3.) Were appropriate statistical tests or descriptive measures used when conducting an analysis of data?

4.) Is GHBS information being disseminated to its intended audience (data end users)?

5.) Is GHBS data being used by its data end users?

A qualitative approach will be used to provide a thorough assessment of the design, implementation and performance of the GHBS project. The qualitative approach consists of conducting key informant interviews with GHBS staff to gather information relevant for addressing evaluation questions. Additionally, data sources will be used to provide credible evidence to further address evaluation questions. Data sources used will be GHBS progress reports and peer reviewed publications. The quantitative method to be used will consist of the administration of surveys to local HIV/AIDS organizations.

The first evaluation question will determine the challenges, if any, that GHBS staff has faced concerning the implementation of the surveillance project. The first evaluation question prompts the interviewee to describe challenges faced during IDU Cycle II and III and what was done to overcome these challenges. The second evaluation question will provide information about key components of the project that must be in place to ensure that objectives and goals are achieved, behavioral characteristics of IDUs, and trends of HIV infection amongst IDUs. The second will provide information concerning whether or not the goals were achieved and if certain goals were not achieved, what factors contributed to these goals not being achieved. The third evaluation question will determine whether or not appropriate statistical tests or descriptive measures were used when conducting an analysis of the data. The data sources to be used to address questions one and two of the set of evaluation questions will be key informant interviews. Information collected from a comprehensive review of GHBS related literature will address the third

evaluation question. The fourth and fifth evaluation questions will determine the intended audience of GHBS and the intended audiences' use (if any) of GHBS related documentation. Conceptually, this evaluation will be done in three strategic ways. First, the evaluation will determine the projects ability to provide information that can be used to accomplish its goals and objectives. Secondly, this evaluation will determine the level of performance of the GHBS project. Lastly, the evaluation will determine the usefulness of the data collected.

Procedures

Evaluation questions one through three will be answered based on information gathered from key informant interviews. Key informant interviews will be conducted with GHBS staff to collect information about key components of the project and differences between IDU Cycle II and IDU Cycle III. Interviews will be conducted face-to face by an evaluator. The interview will be done with GHBS staff; it will last approximately 30 to 45 minutes and will be recorded. Notes will be taken while the interview is being conducted and will be fleshed out immediately after the interview is conducted. Transcription of the interview will be based on the recording of the interview. Information gathered from a thorough review of GHBS related information will address the fourth evaluation question. The last set of evaluation questions will be answered based upon the information gathered from electronic survey. Surveys will be developed via the use of survey monkey and will be disseminated electronically to local HIV/AIDS organizations. Local HIV/AIDS organizations will have three weeks to respond to the survey. Weekly emails will be sent on each Tuesday of that week to remind these organizations to respond to the survey. Once all surveys are complete, the information collected will be analyzed via the use of SPSS.

Instruments

Two data collection tools will be used to gather credible evidence to address evaluation questions. The proposed data collections tools will be an interview guide and an electronic survey. Interview guides developed by the evaluator will be used to conduct key informant interviews with GHBS staff. No more than two to four evaluation questions will be written on the interview guide. Electronic surveys will be disseminated to local HIV/AIDS organizations.

Data Analysis

Information collected from the interview guide and electronic surveys will be used to address evaluation questions. Themes will be formulated from the qualitative methods used and results will be obtained, via the use of SPSS, from the quantitative methods used.

The evaluation of public health surveillance systems should involve an assessment of system attributes, including simplicity, flexibility, data quality, acceptability, sensitivity, predictive value positive, representativeness, timeliness, and stability (*Updated Guidelines for Evaluating Public Health Surveillance Systems*: Recommendations from the Guidelines Working Group. MMWR, 2001). The GHBS public health surveillance system will emphasize those attributes that are most important for the objectives of the system (*Updated Guidelines for Evaluating Public Health Surveillance Systems*: Recommendations from the Guidelines Working Group MMWR, 2001). A comprehensive literature review will determine if these attributes of the surveillance system have been met.

Simplicity

The simplicity of a public health surveillance system refers to both its structure and ease of operation (*Updated Guidelines for Evaluating Public Health Surveillance Systems*: Recommendations from the Guidelines Working Group, MMWR, 2001). Surveillance systems

should be as simple as possible while still meeting their objectives (Updated Guidelines for Evaluating Public Health Surveillance Systems: Recommendations from the Guidelines Working Group, MMWR, 2001). A comparison and contrast between CDC's recommendations of a simple system and what is found in GHBS related documentation will determine the GHBS surveillance systems level of simplicity.

Sensitivity

The sensitivity of a surveillance system can be considered on two levels. First, at the level of case reporting, sensitivity refers to the proportion of cases of a disease (or other health-related event) detected by the surveillance system (*Updated Guidelines for Evaluating Public Health Surveillance Systems*: Recommendations from the Guidelines Working Group, MMWR, 2001). Second, sensitivity can refer to the ability to detect outbreaks, including the ability to monitor changes in the number of cases over time (*Updated Guidelines for Evaluating Public Health Surveillance Systems*: Recommendations from the Guidelines Working Group, MMWR, 2001). GHBS utilizes a data management system that can provide the proportion of cases of HIV/AIDS detected by the surveillance system. A comprehensive literature review of GHBS surveillance can provide information about the changes in the number of cases over time. The information extracted from the literature review will be the rates of HIV/AIDS amongst IDUs in the Atlanta Metropolitan area and any changes with HIV/AIDS rates that have occurred over time from IDU Cycle II to IDU Cycle III.

Representativeness

A public health surveillance system that is representative accurately describes the occurrence of a health-related event over time and its distribution in the population by place and person (*Updated Guidelines for Evaluating Public Health Surveillance Systems*: Recommendations

from the Guidelines Working Group, MMWR, 2001). A comprehensive literature review of GHBS related documentation can provide information about the occurrence of HIV/AIDS from IDU Cycle II to IDU Cycle III.

Timeliness

Timeliness reflects the speed between steps in a public health surveillance system (*Updated Guidelines for Evaluating Public Health Surveillance Systems*: Recommendations from the Guidelines Working Group, MMWR, 2001). GHBS progress reports can determine the timeliness between steps taken to ensure proper implementation of the GHBS project. Progress reports can show what activities (steps) were taken and the amount of time it took to implement one activity prior to implementing the subsequent activity.

Stability

Stability refers to the reliability (i.e., the ability to collect, manage, and provide data properly without failure) and availability (the ability to be operational when it is needed) of the public health surveillance system (*Updated Guidelines for Evaluating Public Health Surveillance Systems*: Recommendations from the Guidelines Working Group, MMWR, 2001). A comprehensive literature review of GHBS related publications and key informant interviews will provide information concerning whether or not the GHBS surveillance project has properly collected, managed, and provided information about HIV/AIDS rates and HIV/AIDS behavioral characteristics amongst IDUs. Additional information that will be collected from GHBS related publications and key informant interviews will be if the surveillance system can be operational when needed.

CHAPTER IV- RESULTS

Introduction

This section will provide the results of the evaluation. Results were determined via the use of qualitative methods, quantitative methods, and the CDC's conceptual framework for evaluation of surveillance systems. Results were obtained from the qualitative methods used which addressed two out five of the evaluation questions. Sub questions were underneath these two overarching questions and were asked by the interviewer. Information gathered from the key informant interviews is written below. Themes were formed by the interviewer and based on the information gathered from the key informant interviews. These sub questions provided the evaluation with more detailed information. (*See appendix B*).

What challenges has GHBS staff encountered concerning the implementation of the GHBS project?

Findings

- Better representation of the targeted population
- The need for additional staff and resources to assist with the dissemination of GHBS data
- During the implementation of the first IDU cycle, there were issues with locating the population

Data Source

Information for this overarching evaluation question was collected via the use of an interview guide. Additionally, there were four sub questions that more directly addressed the overarching evaluation question (*See Appendix B*).

Summary

The challenges that GHBS has faced with the implementation of the project are, concerning the IDU cycle, were locating the population, ensuring that the sample targeted is representative of the Atlanta area, the need for additional staff and resources to improve the implementation of the surveillance project and the dissemination of data/results to the public. GHBS solutions for trying to resolve these issues were to build relationships with organizations that work with the population so that GHBS could get connected with the IDU population and changing site locations to get access to other ethnicities or particular groups of people. The funding for GHBS is restricted to what is set forth in the budget. However, an increase in funds could be allocated toward increasing the incentive for individuals with higher SES to participate in the GHBS study and hiring additional staff to either conduct formative research or disseminate data/results. The strengths of the implementation of the GHBS project are the support that has been given, over time and through developing rapport with CBO's, for implementing the project. The weaknesses of the implementation of the GHBS project finding ways to compete, for prospective participants, with other programs that are conducting similar research in the community. A major strength of the design of the project is that data is being collected from three at risk groups. Two weaknesses of the design of the project are that there is an insufficient number of storefront locations to capture those individuals who live in other counties other than Fulton County and implementing the survey yearly instead of once every three years may be helpful with obtaining more consistent data. GHBS staff informed the interviewer that resources were efficient to meet the enrollment goals for both IDU cycle II and III.

Is the project achieving the goals that have been set forth by the staff and if so, what factors have contributed to the achievement of the goals set forth by GHBS staff?

Findings

- For IDU cycle II and III, the enrollment goal of 500 participants has been achieved
- There are issues with recruiting and screening subjects
- Issues with getting more representation from the Latino population

Data Source

Information for this overarching evaluation question was collected via the use of an interview guide. Additionally, there were seven sub questions that more directly addressed the overarching evaluation question (*See Appendix B*).

Summary

The main goals for the GHBS project are, with each IDU cycle, to reach the enrollment goal of 500 participants, get a more representative sample of the population being targeted, ensuring that proper methods are in use to recruit subjects, and utilizing good skills to avoid errors that occur due to the improper screening of ineligible participants. The GHBS staff has been successful for IDU cycle II and III with reaching the enrollment goal. The success of reaching this enrollment goal is largely due to the fact that the project started on time (in September) which gives GHBS staff the amount of time necessary to recruit, screen, and enroll participants. Increasing the storefronts and hiring bilingual/bicultural staff are solutions needed to reach the Latino population as well as individuals living in counties outside of Fulton County. An issue with the eligibility screening is the fact that the survey is anonymous and so there isn't a perfect way to track individuals who have already done the survey who are trying to sneak and do the survey again. A solution to this would be to have a code word to use amongst staff and when a staff member recognizes an individual who they know for sure that they have previously interviewed.

Thematic Analysis

Costs, representation, and dissemination of data were issues that were mentioned often during the recording of the key informant interviews. Thus, the themes that emerged from the analysis of the qualitative data were cost, representation, and dissemination. GHBS staff mentioned the need to have more funds to increase the incentive for participants and to improve strategies for recruiting participants. GHBS staff was also concerned about the need to have more representation of counties, women, and ethnicities. Having more representation will result in a more representative sample of the IDU population. Lastly, GHBS staff expressed that there is an issue with finding the time to disseminate GHBS data.

Cost

Direct quotes mentioned in this section show GHBS staffs concern with costs:

> "That's one of the things we're looking at for next year um with the MSM cycle is because the incentive amount has not been increased since the beginning its always been twenty five for the survey and then once we implemented the HIV testing, it was twenty five dollars for the testing, so it's never increased."
>
> "I guess potentially with you other resources like our the funding amount again if we could increase the incentives I think that would also maybe draw out some of the people who are sort of hesitant, come out to do the survey it may attract those who are a little bit higher SES who are still actively using"

Representation

Direct quotes mentioned in this section, show GHBS staffs concern with representation:

> "The messages on the tickets making sure that the messages are clear and easy to understand and welcoming for everyone, also having an adequate number of seeds who are from these underrepresented populations"

> "But to get adequate representation you have to be able to survey them in their language, in Spanish so one of the things we did we made sure that we had bilingual and bicultural interviewers you know at least two or three who could speak Spanish and who could would you know help ensure we had a good reputation in the community that yes they are you can do the survey in Spanish and that people would have a good experience with it, they would tell others and….."
>
> "MSA is 28 counties but the picking the-the-the locations for doing the survey as well as picking the times of day to do the survey is-is a challenge and from a design weakness standpoint generally wherever you put the storefront locations you're going to have a good representation of people who live near those storefronts and people who live far away from them who maybe don't have access to public transportation are not going to be adequately represented"

Dissemination

Direct quotes mentioned in this section, show GHBS staffs concern with dissemination of data:

> "Disseminating results from the analysis……Another is generally the….well that would be one of the main ones there might be some others that might come up……..finding time in the calendar to disseminate the results and to analyze the results."

Were appropriate statistical tests or descriptive measures used when conducting an analysis of data?

Findings

- Descriptive measures used were appropriate for conducting an analysis of the data
- The descriptive measures used were percentages and rates of HIV positivity

The comprehensive literature review showed the types of statistical and descriptive measures that were used when conducting an analysis of the data. The statistical measures used were

percentages of HIV/AIDS infection amongst IDUs who completed the survey in 2009. This data was collected from the NHBS system. The report showed that from the 10,073 IDUs interviewed and tested in 20 MSAs in 2009, 9% had a positive HIV test result, and 45% of those testing positive were unaware of their infection (MMWR, 2009). The most current data collected from the GHBS system is for IDU cycle II. The type of statistical measures used there were percentages of HIV/AIDS infection and behavioral characteristics.

Data Source

A comprehensive literature review provided the information to address this evaluation question.

Quantitative Results

The research findings were based on these two evaluation questions which are follows:

1.) Is GHBS information being disseminated to its intended audience (data end users)?

2.) Is GHBS data being used by its data end users?

Is GHBS information being disseminated to its intended audience (data end users)?

Findings

Data from the survey suggest that GHBS data may not be reaching local HIV/AIDS organizations directly since more staff members are unaware of GHBS than those that are aware of GHBS. However, it is not just to make this determination as there is no evidence to show that GHBS data is not being directly disseminated to local HIV/AIDS organizations.

Data Source

This evaluation question was addressed from information collected from key informant interviews and the anonymous survey.

Is GHBS data being used by its data end users?

Two of the four local HIV/AIDS organizations contacted agreed to participate in the survey. The organizations that participated were AID Atlanta and AID Gwinnett. AID Atlanta had a total of 91 staff members who received the survey and AID Gwinnett had a total of 25 staff members who received the survey. Thus, there were a total of 116 staff members that received the survey. The response rate for all staff members combined was 22.4% with 26 out of 116 staff members participating. Staff members who participated were asked a total of 19 questions (*See Appendix C*). SPSS was used to determine the frequency of the quantitative data collected. Results from the survey show that the data has been used by local HIV/AIDS organizations with 27.2% (3/11) of the respondents having used the data in the course of their work activities. Although the percentage rate concerning the use of GHBS data was relatively low (27.2%), the percentage rate concerning the awareness of the GHBS system was greater with 46.2% (12/26) respondents having heard of the GHBS system. The findings from this survey suggest that although HIV/AIDS organizations are aware of the data provided by the GHBS system, the percent of respondents who reported use of the data was low (27.2%). 80% (4/5) of those who reporting using GHBS for specific reasons, used GHBS data to provide health education, preventative techniques, and counseling to individuals infected with HIV/AIDS while 20% (1/5) of the same respondents used GHB data to provide health education to individuals infected with HIV/AIDS. As shown in figure 2, although there isn't a substantial difference between respondents who are aware of the GHBS system and those who are not aware of the system, the response rate for those who were unaware of the system is greater than those who are aware of the system. Figure 3 shows that there is a substantial difference between those who are aware of the GHBS system and their actual of the GHBS data. Table 1 provides the descriptive statistics of responses collected from the knowledge based electronic survey. The number of individuals who

responded to each question, percentage of the response rate, ratio of responses, and cumulative percent are shown in table 1.

Figure 2- Response rate: Awareness of GHBS System

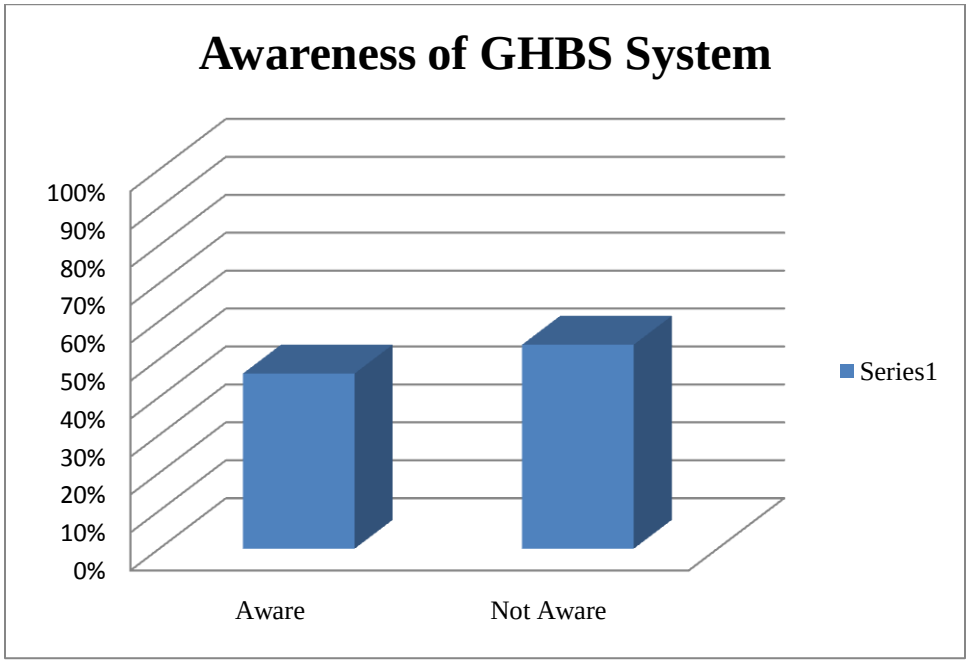
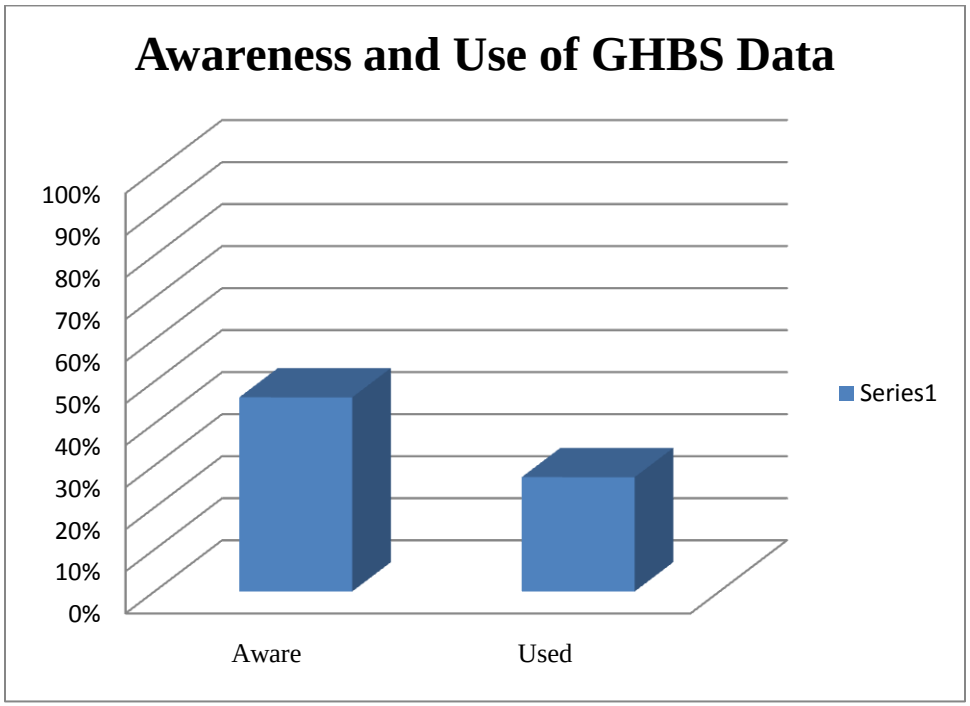


Figure 3- Response Rate: Awareness and Use of GHBS Data



Data Source

This evaluation question was addressed from utilizing data collected from the anonymous survey.

Table 1- Descriptive Statistics of Data Collected from Electronic Survey

Q1Have you ever heard of the Centers for Disease Control and Prevention (CDC)?

N=26	Number of Respondents	Ratio	Response Percentage	Cumulative Percent
No	0			
Yes	26	26/26	100.0%	100.0

Q2Have you ever heard of the Georgia Department of Public Health (GDPH)?

N=26	Number of Respondents	Ratio	Response Percentage	Cumulative Percent
No	0			
Yes	26	26/26	100.0%	100.0

Q3The National HIV Behavioral Surveillance (NHBS) System is an ongoing behavioral surveillance project, managed by the CDC, which collects information about three high risk populations. Have you ever heard of NHBS? If no, skip to question 8.

N=26		Number of Respondents	Ratio	Response Percentage	Cumulative Percent
	No	12	12/26	46.2%	46.2
	Yes	14	14/26	53.8%	53.8
	Total	26	26/26	100.0.%	

Q4Have you ever used NHBS data in the course of your work activities? If no, skip to question 8.

N=13		Number of Respondents	Ratio	Response Percentage	Cumulative Percent
	Skipped	13	13/13	0	50.0
	No	10	10/13	76.9%	88.5
	Yes	3	3/13	23.1%	100.0
	Total	13	100.0	100.0%	

Table 1 Continued - Descriptive Statistics of Data Collected from Electronic Survey

Q5How have you used NHBS data in the course of your work activities?

N=4		Number of Respondents	Ratio	Response Percentage	Cumulative Percent
	Skipped	22	22/22	0	84.6
	Providing information to the public when recruiting for members or Network Association Recruiters	1	1/4	25.0%	88.5
	Sharing statistics with intervention participants	1	1/4	25.0%	92.3
	Statistics for presentations - I think!	1	1/4	25.0%	96.2
	To support grant applications.	1	1/4	25.0%	100.0
	Total	4	4/4	100.0%	

Q6AWhich services, that your organization may provide, have required the use of NHBS data to aid individuals infected with HIV/AIDS?

N=7		Number of Respondents	Ratio	Response Percentage	Cumulative Percent
	Skipped	20	20/20	0	76.9
	All of the above	1	1/3	33.3%	80.8
	Health education	1	1/3	33.3%	84.6
	None of the above	4	4/4	100.0%	100.0
	Total	7	7/7	100.0%	

Q6BWhich services, that your organization may provide, have required the use of NHBS data to aid individuals infected with HIV/AIDS?

N=7		Number of Respondents	Ratio	Response Percentage	Cumulative Percent
	Skipped	25	25/25	0	96.2
	Preventive Techniques	1	1/3	33.3%	100.0
	Total	7	100.0	100.0%	

Table 1 Continued - Descriptive Statistics of Data Collected from Electronic Survey

Q7If you answered "other" to question 6, please explain below:

N=0	Number of Respondents	Ratio	Response Percentage	Cumulative Percent
Skipped	26	26/26	0	100.0

Q8The Georgia HIV Behavioral Surveillance System, managed by the GDPH, is one of 25 sites of the NHBS system that collects data on behavioral characteristics and HIV/AIDS diagnoses. Have you ever heard of GHBS? If no, skip to question 13.

N=26		Number of Respondents	Ratio	Response Percentage	Cumulative Percent
	No	14	14/26	53.8%	53.8
	Yes	12	12/26	46.2%	100.0
	Total	26	26/26	100.0%	

Q9Have you ever used GHBS data in the course of your work activities? If no, skip to question 13.

N=11		Number of Respondents	Ratio	Response Percentage	Cumulative Percent
	Skipped	15	15/15	0	57.7
	No	8	8/11	72.7%	88.5
	Yes	3	3/11	27.3%	100.0
	Total	11	11/11	100.0%	

Q10How have you used GHBS data in the course of your work activities?

N=3		Number of Respondents	Ratio	Response Percentage	Cumulative Percent
	Skipped	23	23/23	0	88.5
	grant writing	1	1/3	33.3%	92.3
	Sharing statistics with intervention participants	1	1/3	33.3%	96.2
	To support grant applications	1	1/3	33.3%	100.0
	Total	3	3/3	100.0%	

Table 1 Continued - Descriptive Statistics of Data Collected from Electronic Survey

Q11Which services, that your organization may provide, have required the use of GHBS data to aid individuals infected with HIV/AIDS?

N=9		Number of Respondents	Ratio	Response Percentage	Cumulative Percent
	Skipped	17	17/17	0	65.4
	All of the above	4	4/9	44.4%	80.8
	Health education	1	1/9	11.1%	84.6
	None of the above	4	4/9	44.4%	100.0
	Total	9	9/9	100.0%	

Q12If you answered "other" to question 11, please explain below:

N=0	Number of Respondents	Ratio	Response Percentage	Cumulative Percent
Skipped	26	26/26	0	100.0

Q13Does your organization work with the following individuals?

N=26		Number of Respondents	Ratio	Response Percentage	Cumulative Percent
	All of the above	25	25/26	96.2%	96.2
	Other	1	1/26	3.8%	100.0
	Total	26	26/26	100.0%	

Q14If you answered "other" to question 13, please explain below:

N=1		Number of Respondents	Ratio	Response Percentage	Cumulative Percent
	Skipped	25	25/25	0	96.2
	Transgendered and lesbians	1	1/26	3.8%	100.0
	Total	1	1/1	100.0%	

Table 1 Continued - Descriptive Statistics of Data Collected from Electronic Survey

Q15Does your organization use any type of HIV/AIDS data to present information and to provide services to individuals infected with HIV/AIDS? (Services include preventive techniques, health education, counseling, needle exchange)

N=26	Number of Respondents	Ratio	Response Percentage	Cumulative Percent
No	0			
Yes	26	26/26	100.0%	100.0

Q16What would be your preferred method of receiving up to date information about behavioral risk factors and rates concerning HIV/AIDS?

N=26		Number of Respondents	Ratio	Response Percentage	Cumulative Percent
	Email	25	25/26	96.2%	96.2
	Other	1	1/26	3.8%	100.0
	Total	26	26/26	100.0%	

Q17If you answered "other" to question 16, please explain below:

N=1		Number of Respondents	Ratio	Response Percentage	Cumulative Percent
	Skipped	25	25/25	0	96.2
	Webinars and e-mail	1	1/1	100.0%	100.0
	Total	1	1/1	100.0%	

Q18How often during a work week do you use HIV/AIDS data/information?

N=26		Number of Respondents	Ratio	Response Percentage	Cumulative Percent
	1-2 times a week	2	2/26	7.7%	7.7
	3-4 times a week	4	4/26	15.4%	23.1
	Daily	13	13/26	50.0%	73.1
	Less than once a week	6	6/26	23.1%	96.2
	Never	1	1/26	3.8%	100.0
	Total	26	26/26	100.0%	

Table 1 Continued - Descriptive Statistics of Data Collected from Electronic Survey

Q19Please leave any comments about your utilization of data that contains information pertaining to behavioral characteristics of individuals infected with HIV/AIDS and HIV/AIDS statistics.

N=3		Number of Respondents	Ratio	Response Percentage	Cumulative Percent
	Skipped	23	23/23	0	88.5
	Case management services	1	1/3	33.3%	92.3
	Gwinnett County behavioral data	1	1/3	33.3%	96.2
	Need for updated data	1	1/3	33.3%	100.0
	Total	3	3/3	100.0%	

CDC Conceptual Framework for Surveillance Systems

Does the GHBS system meet CDC standards for a reliable surveillance system?

Sensitivity

The sensitivity of a surveillance system can be considered on two levels. First, at the level of case reporting, sensitivity refers to the proportion of cases of a disease (or other health-related event) detected by the surveillance system (*Updated Guidelines for Evaluating Public Health Surveillance Systems*: Recommendations from the Guidelines Working Group, MMWR, 2001). Second, sensitivity can refer to the ability to detect outbreaks, including the ability to monitor changes in the number of cases over time (*Updated Guidelines for Evaluating Public Health Surveillance Systems*: Recommendations from the Guidelines Working Group, MMWR, 2001). GHBS utilizes a data management system that can provide the proportion of cases of HIV/AIDS detected by the surveillance system. A comprehensive literature review of GHBS surveillance provided information about the changes in the number of cases over time. The information extracted from the literature review showed the rates of HIV/AIDS amongst IDUs in the Atlanta Metropolitan area and any changes with HIV/AIDS rates that have occurred over time from IDU

Cycle II to IDU Cycle III. The rate of positivity for HIV in the IDU cycle II was 19% (87 participants) (National HIV Behavioral Surveillance System: Injection Drug Users, Fact Sheet IDU 2, 2009). The rate of positivity for HIV in the IDU cycle III is not readily available yet.

Representativeness

A public health surveillance system that is representative accurately describes the occurrence of a health-related event over time and its distribution in the population by place and person (*Updated Guidelines for Evaluating Public Health Surveillance Systems*: Recommendations from the Guidelines Working Group, MMWR, 2001). A comprehensive literature review of GHBS related documentation and information collected from key informant interviews provided information about the representativeness of the IDU population. For many health-related events under surveillance, the proper analysis and interpretation of the data require the calculation of rates (Updated Guidelines for Evaluating Public Health Surveillance Systems: Recommendations from the Guidelines Working Group, MMWR, 2001). The denominators for these rate calculations are often obtained from a completely separate data system maintained by another agency (Updated Guidelines for Evaluating Public Health Surveillance Systems: Recommendations from the Guidelines Working Group, MMWR, 2001). GHBS informed the evaluator that GHBS staff has reached its enrollment goal of 500 participants for IDU cycle II and IDU cycle III. There is somewhat of an issue with representativeness of the sample because the majority of the population is surveyed in areas in Fulton County. However, the CDC and GHBS staff would like to find strategic ways to reach individuals who inject drugs in other counties. However, the staff is limited to conducting research in Fulton County due to costs associated with having multiple storefronts in multiple counties. The GHBS system is representative of the type of population for which they are trying to reach, which is IDUs.

However, there is a challenge with trying to get a more representative sample of women and different ethnicities who inject drugs. Additionally, funding restrictions places limitations on reaching other IDUs who live in the areas outside of Fulton County.

Timeliness

Timeliness reflects the speed between steps in a public health surveillance system (*Updated Guidelines for Evaluating Public Health Surveillance Systems*: Recommendations from the Guidelines Working Group, MMWR, 2001). GHBS progress reports determined the timeliness between steps taken to ensure proper implementation of the GHBS project. Progress reports showed what activities (steps) were taken and the amount of time it took to implement one activity prior to implementing the subsequent activity. The information provided in table 2 was taken from a GHBS interim progress report and shows the steps that were taken to ensure that the majority of the objectives that were set forth by GHBS staff were met.

Table 2- IDU Cycle III Interim Progress Report

Objective 1: By July 31, 2012 Georgia will complete all formative research for the injection drug user population in metro-Atlanta.	Status: Objective met.
Objective 2: By June 30, 2012 Georgia will receive the appropriate Institutional Review Board approvals from the Georgia Department of Public Health to perform behavioral surveillance on injection drug users (IDU3) in metro-Atlanta.	Status: Objective met.
Objective 3: By December 31, 2012, Georgia will attend all CDC scheduled meetings and trainings for the NHBS IDU3 cycle. These	Status: Objective met.

include, but are not limited to, Principal Investigator (PI) meetings, Data Coordinating Center trainings and field operations/interviewer trainings. The team will be available to attend all CDC recommended trainings that will benefit the IDU3 cycle in person or via the internet web-trainings.	
Objective 4: By July31, 2012, Georgia will identify the major injection drug use networks in metro-Atlanta, identify potential seeds to begin the recruiting process for the IDU3 cycle, and obtain information on appropriate locations and hours of operation for field sites/store fronts.	Status: Objective met.
Objective 5: By July 31, 2012, Georgia will collaborate with local researchers, law enforcement officials, social workers, substance abuse prevention/treatment staff, and state program managers for HIV and substance abuse in the development of local questions for the IDU3 local question module. Special emphasis will be placed on involving local researchers and community-based	Status: Objective met.

organizations who work directly with IDU for HIV prevention activities in the metro-Atlanta area. This process will include verifying that proposed prevention questions are relevant and consistent with HIV prevention activities being conducted in metro Atlanta.	
Objective 6: By May 31, 2012, Georgia will recruit, hire, and train necessary staff to conduct Respondent Drive Sampling (RDS) of a minimum of 500 injection drug users in the metro-Atlanta area.	Status: Objective met.
Objective 7: By November 30, 2012, Georgia will interview at least 500 injection drug users to assess HIV risk behaviors among this population in the metro-Atlanta area.	Status: Objective met.
Objective 8: By December 31, 2012, the GHBS team will begin to assess the injection drug use population's HIV testing behaviors and knowledge of and access to HIV prevention programs in the metro Atlanta area.	Status: Objective met.
Objective 9: By December 31, 2012, the GHBS team will assess HIV sero-prevalence	Status: Objective met.

among those sampled in the IDU3 cycle.	
Objective 10: During August to December 2012, the GHBS team will work directly with CDC in evaluating the NHBS system, RDS strategy for IDU3, and data collection methods to ensure the system met its goals. The GHBS team will work with the CDC in making recommendations for improving data quality, efficiency, and usefulness of NHBS data both locally and nationally.	Status: Ongoing, anticipated to be met by December 31, 2012.
Objective 11: By December 31, 2012, the GHBS team will send all IDU3 data to the CDC via the Data Coordinating Center (DCC) Network. The team will follow the guidelines set up by the DCC network and the CDC in completing weekly data uploads. The GHBS team will continue to work with the DCC to correct any errors found in the data.	Status: Ongoing, anticipated to be met by December 31, 2012.
Objective 12: By December 31, 2012, the GHBS team will begin to collaborate with CDC on data analysis and dissemination of results from the IDU3 cycle and, if necessary, any previous cycles of NHBS data.	Status: Ongoing. IDU3 cycle data is still in the clean up phase and has not, as of today, been made available in publications.

Stability

Stability refers to the reliability (i.e., the ability to collect, manage, and provide data properly without failure) and availability (the ability to be operational when it is needed) of the public health surveillance system (*Updated Guidelines for Evaluating Public Health Surveillance Systems*: Recommendations from the Guidelines Working Group, MMWR, 2001). A comprehensive literature review of GHBS related publications and key informant interviews provided information concerning whether or not the GHBS surveillance project has properly collected, managed, and provided information about HIV/AIDS rates and HIV/AIDS behavioral characteristics amongst IDUs. Additional information that will be collected from GHBS related publications and key informant interviews will be if the surveillance system can be operational when needed. Based on a review of the literature, the NHBS surveillance system has provided a plethora of peer reviewed articles that show that the surveillance system is both reliable and available. One study, done in the Seattle area showed that there was consistency over time with the responses given from IDU surveys from IDU cycle II to IDU cycle III. This study showed that NHBS-IDU2 participants were more likely than NHBS-IDU1 participants to report older age, heroin as their primary injection drug, male-to-male sex, unprotected sex with a partner of nonconcordant HIV status, and to self-report HIV-positive status (Burt & Thiede, 2012). Since the inception of the NHBS system, formative research has been done on the IDU population to ensure that adequate information can be used to understand and subsequently recruit the IDU population (i.e. where they live, where they hang out) A number of preparatory activities preceded implementation of the NHBS-IDU surveillance cycle, including pilot studies, formative assessment (to better understand the population of interest in terms of demographic characteristics, and to identify and map locations where the target population could be reached), literature review, and expert consultation. For NHBS-IDU, the surveillance activities with the

population of interest include recruitment, eligibility assessment, and administration of a behavioral survey (Lanksy et al, 2007). Data management and analysis are conducted jointly between CDC and the participating NHBS sites (Lanksy et al, 2007). GHBS has consistently collected data of HIV/AIDS rates and HIV/AIDS behavioral characteristics. The information collected consisted of HIV positivity rates (both new and existing infections), and at risk behaviors i.e. sharing syringes, having unprotected sex with other IDUs, and sharing drug equipment. GHBS has information in the form of a fact sheet about IDU cycle II that is readily available for the public. However, information about IDU III is not readily available since this survey was just administered in 2012 and most of the data is in the clean up phase.

CHAPTER V- DISCUSSION

Introduction

The purpose of this study is to conduct an evaluation of key components of the GHBS project. Additionally, this study proposes to determine the level of performance of the GHBS project and the usefulness of the data collected by the GHBS system. A logic model provided guidance for the evaluation of this surveillance project. Results from evaluation questions show that the GHBS project is for the most part reaching its goals and objectives; however, there are some issues with the IDU sample size being more representative of the MSA, allocation of funds to increase participation rates and improve strategies for recruiting participants, and dissemination of data to local HIV/AIDS organizations. The level of performance of the GHBS system was determined by the CDC's framework for surveillance systems. Only those attributes that were relevant to the GHBS system were utilized. Information collected from publications and key informant interviews show that the GHBS system meets the requirements set by CDC for the sensitivity, representativeness, timeliness, and stability of a surveillance system. However, representativeness is an issue for the surveillance system since the population sampled is most representative of Fulton County residents than other counties in the MSA area. Results from the survey show that percentage rates concerning the awareness of the GHBS system are higher than the percentage rates concerning the utilization of GHBS data.

Summary of Study

The study is an evaluation of a surveillance project, with emphasis being placed on the IDU component of the surveillance project. A mixed methods approach was used to collect and analyze the data. Data was collected via the use of key informant interviews and an electronic survey. Key informant interviews were conducted face-to-face and recorded while the electronic

survey was sent via mass email to the staff of local HIV/AIDS organizations. Results show that there are issues with representativeness, cost, and dissemination of data. The implementation of strategies mentioned from GHBS staff during key informant interviews may help to resolve some of the issues with representativeness, cost, and dissemination of data.

Recommendations

Recommendations to the stakeholders include, but are not limited to, implementing specific strategies to address issues of representativeness, cost, and dissemination of data.

Recommendations from GHBS staff and Evaluator

Representativeness

- Opening up other storefront locations in counties outside of Fulton County
- Continuing to hire bilingual/bicultural staff who can communicate with individuals in the Latino community who inject drugs
- For IDU cycle IV, opening up a storefront location in DeKalb County.

The benefits of implementing these two strategies can help GHBS staff to target more individuals who inject drugs, which will result in a higher probability of reaching a more representative sample of IDUs who are Latino and/or live in multiple counties. During the implementation of previous IDU cycles, there were two storefront locations that were open to prospective participants. For IDU cycle IV, the evaluator's suggestion would be to keep one storefront location open in the "bluff" area where there is a high IDU population and open up a new storefront location in DeKalb County. Opening up a storefront location in DeKalb County will help GHBS staff to reach IDUs who live in a county outside of Fulton County. Reaching individuals in another county will help to improve the representation of the IDU population.

Costs

- Allocating funds to increase incentives for participants
- Allocating funds to improve recruiting of IDUs
- The evaluator is in agreement with GHBS staff concerning allocating funds accordingly to improve recruitment strategies.

An increase in the gift card amount can be an incentive for IDUs with a higher SES to want to participate in the survey. With regard to the challenges faced with recruitment, GHBS staff stated during the interview that a solution that may or may not be adopted is to have a video inputted in an IPACK device and shown to participants concerning what they should and should not do when recruiting other individuals who inject drugs to participate in the survey. Inputting the video in the IPACK device comes with its limitations because the sound of the device can only reach a certain level and so if it's noisy during the process of explaining recruitment, then the participant may not be able to hear the video. Funds can be allocated accordingly if another grant is received to provide funds for improving recruitment strategies. Another recommendation would be for GHBS staff to do an assessment of the budget and see what funds can be distributed from one expenditure to the expenditure for "recruiting" participants.

Dissemination of Data

- Need to devote time to the dissemination of GHBS data
- Funding can be used to hire additional staff to help disseminate the data to local HIV/AIDS organizations.
- If there is an issue with not having sufficient funds to hire additional staff, another option would be to hire a graduate student as an unpaid intern.
- Disseminate data via email and/or webinars to local HIV/AIDS organizations.

GHBS staff expressed having the desire to want to actively disseminate GHBS data to the general public. However, there is a concern with trying to find the time to devote to the dissemination of GHBS data. Hiring additional staff to help with the dissemination of data will resolve the issue of not having someone to devote time to the active dissemination of data. This additional staff member could solely devote their time to disseminating GHBS information/data to the general public. If there is an issue with not having sufficient funds to hire an additional staff member, then GHBS can hire a student to devote their time to disseminating data to the general public. The internship would be unpaid; nonetheless, the student would be able to gain relevant public health experience with working on a HIV/AIDS surveillance project.

The local HIV/AIDS organizations' preferred method of receiving GHBS related data would be email and webinars. The continuous flow of the dissemination of data as well as the receipt of more up to date data via email and webinars may influence staff of local HIV/AIDS organizations to increase their knowledge and utilization of GHBS data.

Limitations

Limitations of the evaluation consist of the sample size (N=28) for the survey and the key informant interviews lacking representativeness of a larger sample size. It would have been beneficial if more local HIV/AIDS organizations and GHBS staff could have participated in the survey. Although four out of five local HIV/AIDS organizations were contacted, time constraints did not allow for more than two out of five local organizations to participate. Another limitation to the evaluation was the fact that certain data sources that were needed were not available. Having access to certain data sources would have helped to further address the surveillance systems ability to meet CDC's criteria for surveillance systems.

Conclusions

The GHBS surveillance project is, for the most part, meeting the goals and objectives set forth by GHBS staff. Information collected from the key informant interviews and electronic survey shows that overall, the surveillance project is operating successfully. However, there are some areas of concern such as representativeness, cost, and dissemination of data that need to be addressed to improve the efficacy of the surveillance project.

APPENDIX A

Frequency Tables

Q1Have you ever heard of the Centers for Disease Control and Prevention (CDC)?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	26	100.0	100.0	100.0

Q2Have you ever heard of the Georgia Department of Public Health (GDPH)?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	26	100.0	100.0	100.0

Q3The National HIV Behavioral Surveillance (NHBS) System is an ongoing behavioral surveillance project, managed by the CDC, which collects information about three high risk populations. Have you ever heard of NHBS? If no, skip to question 8.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	12	46.2	46.2	46.2
	Yes	14	53.8	53.8	100.0
	Total	26	100.0	100.0	
N= 26					

Q4Have you ever used NHBS data in the course of your work activities? If no, skip to question 8.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid		13	50.0	50.0	50.0
	No	10	38.5	38.5	88.5
	Yes	3	11.5	11.5	100.0
	Total	26	100.0	100.0	
N=26					

Q5How have you used NHBS data in the course of your work activities?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid		22	84.6	84.6	84.6
	Providing information to the public when recruiting for members or Network Association Recruiters	1	3.8	3.8	88.5
	Sharing statistics with intervention participants	1	3.8	3.8	92.3
	Statistics for presentations - I think!	1	3.8	3.8	96.2
	To support grant applications.	1	3.8	3.8	100.0
	Total	26	100.0	100.0	

Q6AWhich services, that your organization may provide, have required the use of NHBS data to aid individuals infected with HIV/AIDS?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid		20	76.9	76.9	76.9
	All of the above	1	3.8	3.8	80.8
	Health education	1	3.8	3.8	84.6
	None of the above	4	15.4	15.4	100.0
	Total	26	100.0	100.0	
N=8					

Q6BWhich services, that your organization may provide, have required the use of NHBS data to aid individuals infected with HIV/AIDS?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid		25	96.2	96.2	96.2
	Preventive Techniques	1	3.8	3.8	100.0
	Total	26	100.0	100.0	
N=1					

Q7If you answered "other" to question 6, please explain below:

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid	26	100.0	100.0	100.0

Q8The Georgia HIV Behavioral Surveillance System, managed by the GDPH, is one of 25 sites of the NHBS system that collects data on behavioral characteristics and HIV/AIDS diagnoses. Have you ever heard of GHBS? If no, skip to question 13.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	14	53.8	53.8	53.8
	Yes	12	46.2	46.2	100.0
	Total	26	100.0	100.0	
N=26					

Q9Have you ever used GHBS data in the course of your work activities? If no, skip to question 13.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid		15	57.7	57.7	57.7
	No	8	30.8	30.8	88.5
	Yes	3	11.5	11.5	100.0
	Total	26	100.0	100.0	
N=11					

Q10How have you used GHBS data in the course of your work activities?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid		23	88.5	88.5	88.5
	grant writing	1	3.8	3.8	92.3
	Sharing statistics with intervention participants	1	3.8	3.8	96.2
	To support grant applications	1	3.8	3.8	100.0
	Total	26	100.0	100.0	
N=3					

Q11Which services, that your organization may provide, have required the use of GHBS data to aid individuals infected with HIV/AIDS?

		Frequency	Percent	Valid Percent	Cumulative Percent
		17	65.4	65.4	65.4
	All of the above	4	15.4	15.4	80.8
Valid	Health education	1	3.8	3.8	84.6
	None of the above	4	15.4	15.4	100.0
	Total	26	100.0	100.0	
N=9					

Q12If you answered "other" to question 11, please explain below:

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid	26	100.0	100.0	100.0

Q13Does your organization work with the following individuals?

		Frequency	Percent	Valid Percent	Cumulative Percent
	All of the above	25	96.2	96.2	96.2
Valid	Other	1	3.8	3.8	100.0
	Total	26	100.0	100.0	
N=26					

Q14If you answered “other” to question 13, please explain below:

		Frequency	Percent	Valid Percent	Cumulative Percent
		25	96.2	96.2	96.2
Valid	Transgendered and lesbians	1	3.8	3.8	100.0
	Total	26	100.0	100.0	
N=1					

Q15Does your organization use any type of HIV/AIDS data to present information and to provide services to individuals infected with HIV/AIDS? (Services include preventive techniques, health education, counseling, needle exchange)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	26	100.0	100.0	100.0
N=26					

Q16What would be your preferred method of receiving up to date information about behavioral risk factors and rates concerning HIV/AIDS?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Email	25	96.2	96.2	96.2
	Other	1	3.8	3.8	100.0
	Total	26	100.0	100.0	
N=26					

Q17If you answered "other" to question 16, please explain below:

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid		25	96.2	96.2	96.2
	Webinars and e-mail	1	3.8	3.8	100.0
	Total	26	100.0	100.0	
N=1					

Q18How often during a work week do you use HIV/AIDS data/information?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1-2 times a week	2	7.7	7.7	7.7
	3-4 times a week	4	15.4	15.4	23.1
	Daily	13	50.0	50.0	73.1
	Less than once a week	6	23.1	23.1	96.2
	Never	1	3.8	3.8	100.0
	Total	26	100.0	100.0	
N=26					

Q19Please leave any comments about your utilization of data that contains information pertaining to behavioral characteristics of individuals infected with HIV/AIDS and HIV/AIDS statistics.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid		23	88.5	88.5	88.5
	Case management services	1	3.8	3.8	92.3
	Gwinnett County behavioral data	1	3.8	3.8	96.2
	Need for updated data	1	3.8	3.8	100.0
	Total	26	100.0	100.0	

APPENDIX B

Interview Guide

Interviewer: Lennisha Pinckney
Interviewee: GHBS staff

Start Time:

End Time:

Overarching Evaluation Questions

What challenges has GHBS staff encountered concerning the implementation of the GHBS project?

Is the project achieving the goals that have been set forth by the staff and if so, what factors have contributed to the achievement of the goals set forth by GHBS staff?

Questions

1.) What challenges has GHBS staff encountered concerning the implementation of the GHBS project?

   a) Since its inception, what challenges (if any) has GHBS encountered during the implementation of this surveillance project?
   b) Describe the type of strategies that were used to overcome these challenges?
   c) What are the strengths and weaknesses of the design and implementation of the GHBS project? Probe-Any areas of improvement?
   d) For the IDU cycle II and III, were the resources efficient enough to uphold the activities of the project?

2.) Is the project achieving the goals that have been set forth by the staff and if so, what factors have contributed to the achievement of the goals set forth by GHBS staff?

   a) What were your goals for IDU Cycle II and III? What factors contributed to the achievement of these goals?
   b) Describe the roles and responsibilities of GHBS staff? Do you feel that the project is adequately staffed to reach the goals and objectives of the project?
   c) Who are the relevant stakeholders for the project? What is their level of involvement in the project?

d) What eligibility screening tools are used and are these tools sufficient to avoid any errors for enrolling participants?
e) Describe for me the methods for recruiting subjects? What are the strengths and weaknesses for using these methods to recruit subjects?
f) Describe for me the reliability and availability of the surveillance system?
g) Who develops the survey questions?
   Probe
   Describe for me concerning what has been discovered about the behavioral characteristics that impact HIV/AIDS infection amongst IDUs.
   Describe for me concerning what has been discovered about the HIV/AIDS trends amongst IDUs.

APPENDIX C

Knowledge-based Questions

Survey monkey

1.) Have you ever heard of the Centers for Disease Control and Prevention (CDC)?
2.) Have you ever heard of the Georgia Department of Public Health (GDPH)?
3.) The National HIV Behavioral Surveillance (NHBS) System is an ongoing behavioral surveillance project, managed by the CDC, which collects information about three high risk populations. Have you ever heard of NHBS? If no, skip to question 8.
4.) Have you ever used NHBS data in the course of your work activities? If no, skip to question 8.
5.) How have you used NHBS data in the course of your work activities?
6.) Which services, that your organization may provide, have required the use of NHBS data to aid individuals infected with HIV/AIDS?

    Health education
    Preventive Techniques
    Counseling
    All of the above
    None of the above
    Other (Please Explain)_____

7.) If you answered "other" to question 6, please explain below:
8.) The Georgia HIV Behavioral Surveillance System, managed by the GDPH, is one of 25 sites of the NHBS system that collects data on behavioral characteristics and HIV/AIDS diagnoses. Have you ever heard of GHBS? If no, skip to question 13.
9.) Have you ever used GHBS data in the course of your work activities? If no, skip to question 13.
10.) How have you used GHBS data in the course of your work activities?
11.) Which services, that your organization may provide, have required the use of GHBS data to aid individuals infected with HIV/AIDS?

    Health education
    Preventive Techniques
    Counseling
    All of the above
    None of the above
    Other (Please Explain)_____

12.) If you answered "other" to question 11, please explain below:
13.) Does your organization work with the following individuals?

Injection Drug Users (IDUs)
Men who have sex with men (MSM)
Heterosexuals
All of the above
Other (Please Explain)_____

14.) If you answered "other" to question 13, please explain below:
15.) Does your organization use any type of HIV/AIDS data to present information and to provide services to individuals infected with HIV/AIDS? (Services include preventive techniques, health education, counseling, needle exchange)
16.) What would be your preferred method of receiving up to date information about behavioral risk factors and rates concerning HIV/AIDS?

Phone
Email
Mail
Other (Please Explain)_____

17.) If you answered "other" to question 16, please explain below:
18.) How often during a work week do you use HIV/AIDS data/information?

Never
Less than once a week
1-2 times a week
3-4 times a week
Daily

19.) Please leave any comments about your utilization of data that contains information pertaining to behavioral characteristics of individuals infected with HIV/AIDS and HIV/AIDS statistics.

APPENDIX D

EMORY UNIVERSITY

Institutional Review Board

September 6, 2013

Lennisha Pinckney
Principal Investigator
GYN ONCOLOGY

RE: **Exemption of Human Subjects Research**

IRB00062756

Evaluation of the Georgia HIV Behavioral Surveillance (GHBS) System

Dear Principal Investigator:

Thank you for submitting an application to the Emory IRB for the above-referenced project. Based on the information you have provided, we have determined on September 6, 2013 that although it is human subjects research, it is exempt from further IRB review and approval.

This determination is good indefinitely unless substantive revisions to the study design (e.g., population or type of data to be obtained) occur which alter our analysis. Please consult the Emory IRB for clarification in case of such a change. Exempt projects do not require continuing renewal applications.

This project meets the criteria for exemption under 45 CFR 46.101(b)(2). Specifically, you will conduct Interviews and survey procedures to evaluate the program at the GA HIV Behavioral Surveillance System (GHBS). The purpose it to make recommendations to the GHBS staff only and the recommendations will be in the body of the thesis as well as the presentation. No sensitive data will be collected.

Please note that the Belmont Report principles apply to this research: respect for persons, beneficence, and justice. You should use the informed consent materials reviewed by the IRB unless a waiver of consent was granted. Similarly, if HIPAA applies to this project, you should use the HIPAA patient authorization and revocation materials reviewed by the IRB unless a

waiver was granted. CITI certification is required of all personnel conducting this research.

Unanticipated problems involving risk to subjects or others or violations of the HIPAA Privacy Rule must be reported promptly to the Emory IRB and the sponsoring agency (if any).

In future correspondence about this matter, please refer to the study ID shown above. Thank you.

Sincerely,

Brandy Covington, BBA, CIP
Research Protocol Analyst, Sr.
This letter has been digitally signed

Emory University
1599 Clifton Road, 5th Floor - Atlanta, Georgia 30322
Tel: 404.712.0720 - Fax: 404.727.1358 - Email: irb@emory.edu - Web: http://www.irb.emory.edu/

Georgia Department of Public Health

Brenda Fitzgerald, MD, Commissioner | Nathan Deal, Governor
2 Peachtree Street NW, 15th Floor
Atlanta, Georgia 30303-3142
www.health.state.ga.us

September 12, 2013

Lennisha Pinckney
MPH Candidate
Emory University
Rollins School of Public Health

Project: **130801 - Evaluation of the Georgia HIV Behavioral Surveillance (GHBS) System**

Project Status: Approved Until **09/12/2014**

Dear Researcher,

The above-referenced project was reviewed by the DPH Institutional Review Board in accordance with expedited review procedures outlined in 45 CFR 46.110(b)(1), category(ies) **6&7**
The Board has approved this study until 09/12/2014

If you wish to continue this project beyond the current approval period, please submit a "Continuing Review Application" before the above expiration date. If you do not submit a renewal application before the expiration date, the approval of your project will automatically terminate. Any involvement with human subjects must cease on the above date unless you have received approval from the Board to continue the project. It is the investigators responsibility to track the deadline.

This approval applies only to the protocol described in your application. IRB review and approval is required before implementing any changes in this project except where necessary to eliminate apparent immediate hazards to human subjects.

If you have any questions regarding this letter or general procedures, please contact the DPH IRB at irb@dhr.state.ga.us. Please reference the project # in your communication.

Best wishes in your research endeavors,

Brian Kirtland, Ph.D.

APPENDIX E

Study No.: IRB00060297 *Emory University IRB* Document Approved On: 9/21/2012
IRB use only

Emory University
Consent to be a Research Subject

Title: **Evaluation of the Georgia HIV Behavioral Surveillance (GHBS) System**

Principal Investigator: Lennisha Pinckney, MPH Candidate

Introduction

You are being asked to be in a research study. This form is designed to tell you everything you need to think about before you decide to consent (agree) to be in the study or not to be in the study. **It is entirely your choice. If you decide to take part, you can change your mind later on and withdraw from the research study. You can skip any questions that you do not wish to answer.**

Before making your decision:

- Please carefully read this form or have it read to you
- Please ask questions about anything that is not clear

You can take a copy of this consent form, to keep. Feel free to take your time thinking about whether you would like to participate. By signing this form you will not give up any legal rights.

Study Overview

The purpose of this study is to conduct an evaluation of key components of the GHBS surveillance project. Additionally, this study proposes to determine what key components have contributed to the efficacy of the GHBS surveillance project.

Procedures

This study will administer key informant interviews and a survey. GHBS staff will be interviewed once for approximately 30 to 45 minutes. The key informant interviews will be in person and will be recorded. GHBS staff will be asked questions about the implementation of the GHBS project.

Risks and Discomforts

There is minimal risk in this study. However, answering questions may cause some frustration or anxiety for some people. If you feel uncomfortable, you can refuse to answer any questions or stop the interview or survey at any time.

Benefits

This study is not designed to benefit you directly. This study is designed to learn more about the efficacy of the GHBS project. The study will determine the utilization of GHBS data by local HIV/AIDS organizations.

Confidentiality

If you agree to participate all facts about you will be kept confidential. Information collected from the key informant interviews will be reported in aggregate and all personal identifiers will be removed. Tape recordings will be stored in a secured locked file cabinet. Emory will keep any research records private to the extent that we are required by law.

Voluntary Participation and Withdrawal from the Study

You have the right to leave the study at any time without penalty. You may refuse to answer any questions that you do not wish to answer. You have the right to request that the information not be used if you decide to withdraw your participation.

Contact Information

Contact Lennisha Pinckney at 404-245-1739 or Iris Smith at 404-727-2925:

- If you have any questions about this study or your part in the study.
- If you have questions, concerns or complaints about the research.

Contact the Emory Institutional Review Board at 404-712-0720 or irb@emory.edu:

- If you have questions about your rights as a research participant.
- If you have questions, concerns or complaints about the research.
- You may also let the IRB know about your experience as a research participant through our Research Participant Survey at http://www.surveymonkey.com/s/6ZDMW75.

Consent

Please, print your name and sign below if you agree to be in this study. By signing this consent form, you will not give up any of your legal rights. We will give you a copy of the signed consent, to keep.

_____

Name of Subject

_____ _____

Signature of Subject Date Time

_____ _____

Signature of Person Conducting Informed Consent Discussion Date Time

APPENDIX F

Study No.: IRB00060297 *Emory University IRB* Document Approved On: 9/21/2012
IRB use only

Emory University
Consent to be a Research Subject

August 2013

Greetings,

My name is Lennisha Pinckney and I am a graduate student at Emory University. I am working on a thesis project in partial fulfillment for my Master's in Public Health (MPH) degree. My thesis project requires some data collection and so I am writing this letter to ask your permission to administer an electronic survey to your staff. **It is entirely your choice. If you decide to take part, you can change your mind later on and withdraw from the research study. You can skip any questions that you do not wish to answer.** If you choose to participate you can click the link that is provided below and by clicking the link this is an indication of your consent to take the survey.

https://www.surveymonkey.com/s/YVXV7WD

The survey is knowledge based and contains approximately 19 questions. To protect your privacy, the survey is anonymous and no personal identifying information will be collected. The information reported will be in aggregate form. The evaluation team will solely have access to your individual responses. Emory will keep any research records private to the extent that we are required by law.

There is a time limit to complete the survey which is three weeks and a friendly email will be sent once a week to encourage the staff to complete the survey. There is minimal risk in this study. However, answering questions may cause some frustration or anxiety for some people. If you feel uncomfortable, you can refuse to answer any questions or stop the survey at any time. This study is not designed to benefit you directly. This study is designed to learn more about the efficacy of the GHBS project. The study will determine the utilization of GHBS data by local HIV/AIDS organizations.

You have the right to withdraw your participation at any time without penalty. You may refuse to answer any questions that you do not wish to answer. You have the right to request that the information not be used if you decide to withdraw your participation.

You can contact Lennisha Pinckney at 404-245-1739 or Iris Smith at 404-727-2925:

- If you have any questions about this survey,
- Your participation in the survey,
- If you have any questions, complaints, or concerns about the research.

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Contact the Emory Institutional Review Board at 404-712-0720 or irb@emory.edu:

- If you have questions about your rights as a research participant.
- If you have questions, concerns or complaints about the research.
- You may also let the IRB know about your experience as a research participant through our Research Participant Survey at http://www.surveymonkey.com/s/6ZDMW75.

Warmest Regards,

Lennisha Pinckney

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