An Exploration of the Implementation and Effects of the North Carolina HIV Control Measures

by

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Carolyn McAllaster

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Christopher Woods

Thesis submitted in partial fulfillment of the requirements for the degree of Master of Science in the Duke Global Health Institute in the Graduate School of Duke University.

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ABSTRACT

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Abstract

Since the beginning of the AIDS epidemic, governmental authorities across the country have attempted to legislate the behavior of HIV-positive individuals. North Carolina’s HIV Control Measures exemplify this type of legislative endeavor. The North Carolina Legislature gave the North Carolina Commission for Public Health statutory authority to promulgate control measures for HIV/AIDS. The resulting HIV Control Measures (“control measures”) are rules that govern the actions of HIV-positive individuals, their physicians, their partners, and state health officials and are meant to limit the spread of the disease. While these control measures were implemented to accomplish legitimate public health objectives, there has been very little research evaluating the extent to which they have fulfilled, or failed to fulfill, these goals.

This project represents the beginning of an exploration of the ways that the control measures affect HIV policy in North Carolina. This study used a combination of qualitative interviews and legal research to better understand the on-the-ground implementation of the control measures and the ways that they affect the public health of both HIV-infected and HIV-uninfected individuals in the state. The results of the study include a consideration of the positive duties required of HIV-infected individuals under the control measures. Additional themes, such as recent scientific data on HIV treatment and the effect of the Internet on HIV generally, are also considered. Finally, overall thematic conclusions are offered and suggestions for subsequent explorations are presented.
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1. Introduction

The North Carolina HIV Control Measures were implemented in 1988. These control measures outline the legal duty of HIV-positive individuals, their health care providers and various government officials, such as county health directors. The control measures stipulate that HIV-positive individuals shall:

(a) “refrain from sexual intercourse unless condoms are used; exercise caution when using condoms due to possible condom failure;
(b) not share needles or syringes, or any other drug-related equipment, paraphernalia, or works that may be contaminated with blood through previous use;
(c) not donate or sell blood, plasma, platelets, other blood products, semen, ova, tissues, organs, or breast milk;
(d) have a skin test for tuberculosis;
(e) notify future sexual intercourse partners of the infection;
(f) if the time of initial infection is known, notify persons who have been sexual intercourse and needle partners since the date of infection; and,
(g) if the date of initial infection is unknown, notify persons who have been sexual intercourse and needle partners for the previous year.”

These control measures can be categorized into three types of legal stipulations for HIV-positive individuals in North Carolina: (1) prohibitions on activities that are

1 For full text of the North Carolina HIV Control Measures, please see Appendix A.
2 10A NCAC 41A .0202, “Control Measures – HIV.”
illegal for all individuals, regardless of their HIV status (e.g., no sharing of needles utilized for illegal drugs\(^3\)); (2) prohibitions on activities that are legal but-for an HIV-positive status (e.g., no blood donation); and (3) affirmative duties\(^4\) for HIV-positive individuals (e.g. disclosure of status to sexual partners). This study will focus on the final category, which includes the requirements that HIV-infected individuals use condoms when engaging in sexual intercourse, disclose their HIV-positive status to future sex partners, and notify past partners of their diagnosis.

This paper attempts to answer the following questions:

1) How are these “affirmative duty” control measures implemented and enforced on the ground?

2) To what extent do these control measures fulfill (or fail to fulfill) public health goals surrounding the control, mitigation, and eradication of HIV?

\(^3\) The sharing of needles for legal reasons, such as between diabetics, would fall into the second category: prohibitions that are legal but-for an HIV-positive status.

\(^4\) While much of the law in this country tells us what we may not do, some laws establish affirmative duties – or things that certain individuals are required to do under the law.
2. Background

2.1 The North Carolina AIDS Epidemic

There are approximately 50,000 new cases of HIV in the United States annually, a number that has been stable for over a decade.\(^1\) At the end of 2008, the most recent year for which national prevalence estimates are available, approximately 1.2 million individuals were infected with HIV in the U.S. In 2010, there were 1,487 new reported cases of HIV in North Carolina.\(^2\) This number has also remained relatively stable since approximately 2006.\(^3\) Fifty-seven percent of these cases occurred in men who have sex with men (MSM). As of December 2010, the reported number of individuals living with HIV in North Carolina was 25,074; however, because many infected individuals are unaware of their status, the actual number is thought to be higher.

North Carolina’s AIDS epidemic is one of the worst in the country.\(^4\) As of 2010, the most recent year for which statistics have been published by North Carolina Health & Human Services, the estimated number of people living with reported cases of HIV was 25,074.\(^5\) Between 2008 and 2010 the average rate of diagnosed HIV cases in the state was 17.6 per 100,000 population.\(^6\) Durham County, in which six of the interviews for this

\(^6\) Id.
study took place, had the third highest rate of any county in North Carolina during that period, with 33.7 cases per 100,000 population.\textsuperscript{7} In 2010, African Americans represented 66\% of all known cases of HIV in North Carolina. The highest rate of new infection was among adult and adolescent African American males.\textsuperscript{8}

\textbf{2.2 Legislative History}

Except for certain public health measures that are implemented on a national level, such as Medicaid, FDA regulations, etc., individual states are given a fair amount of leeway in establishing their own public health schemes. However, these state-defined public health systems are still influenced by the Federal Government, both through Administrative Agency recommendations (e.g. the Center for Disease Control (CDC)), and by federal funding that has certain contingencies (e.g. Ryan White funding). The Center for Disease Control publishes recommendations and guidelines on many HIV-related topics, including testing, partner services, and treatment.\textsuperscript{9} North Carolina has, on multiple occasions, changed its regulations to match certain recommendations made by the CDC.\textsuperscript{10} The Ryan White Care Act, first enacted in 1990, established nation-wide funding to serve HIV-positive individuals who are “low income, are un- or underinsured, or otherwise lack the resources to access services on their own.”\textsuperscript{11} This was a prime example of the way that the federal government influences state public health policy, as

\textsuperscript{7} Id.
\textsuperscript{8} Id.
\textsuperscript{10} Examples of these recommendations will be described later in this section.
the Act required states to have a “stated capacity to prosecute those who ‘intentionally transmit’ the virus” in order to be eligible to receive funding.\textsuperscript{12}

State law, however, governs the way that North Carolina \textit{generally} deals with its own HIV epidemic. Under North Carolina General Statute 130A-144, the North Carolina Commission for Public Health is required to adopt “rules that prescribe control measures for communicable diseases and conditions.”\textsuperscript{13} These rules are to be enforced by the local health director. The North Carolina Commission for Public Health is an administrative agency, and the control measures are therefore administrative regulations.

The North Carolina Commission for Public Health consists of thirteen members at any given time; four are elected by the North Carolina Medical Society and nine are appointed by the Governor. The control measures went through the standard North Carolina administrative procedure, both at the time of their inception and whenever they have been amended. Without delving too deeply into administrative law process, this essentially means that, wielding authority given to them by the State Legislature, the Commission drafted a set of rules. These rules were then published in the North Carolina Register and went through a “notice and comment” period, during which time the public had the opportunity to provide feedback. Subsequent to this notice and comment period, the rules were officially added to the North Carolina Administrative Code.

The North Carolina Commission for Public Health was given the authority to promulgate HIV-specific control measures through a series of statutes passed by the

\begin{footnotesize}
\begin{itemize}
\item[13] N.C.G.S. 130A-144.
\end{itemize}
\end{footnotesize}
North Carolina General Assembly.¹⁴ N.C.G.S. 130A-144 instructs the Commission to “adopt rules that prescribe control measures for communicable diseases and conditions subject to the limitations of N.C.G.S. 130A-148.” Under N.C.G.S. 130A-135, the General Assembly required the Commission to “declare confirmed HIV infection to be a reportable communicable condition.” These two statutes, when taken in combination, gave the Commission express permission to prescribe control measures for HIV.

The statutory authority that the North Carolina General Assembly gave the Commission also provided certain limitations and requirements. These include the stipulation that physicians must report cases of communicable diseases to the local health director, who in turn must investigate reported cases.¹⁵ The establishing statutes also require physicians to provide the control measures to a newly infected individual.¹⁶ The Commission included both of these provisions in the control measures. Outside of the requirements specifically outlined by the legislature, it was up to the Commission to flesh out the rules, and it is this organization that ultimately determined the various requirements for HIV-positive individuals that are listed above.

In addition to giving the Commission the power to promulgate control measures, and stipulating some of the requirements that must be included in the same, the statutes also restricted the Commission’s power in certain ways. For example, the control measures were required to be compatible with State statutes governing the laboratory tests for

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¹⁴ N.C.G.S. 130A-135, N.C.G.S. 130A-144, N.C.G.S. 130A-148(h). The complete language of these statutes is included in Appendix B.
¹⁵ N.C.G.S. 130A-144.
¹⁶ N.C.G.S. 130A-135.
AIDS infection\textsuperscript{17} and the confidentiality of AIDS-related medical records\textsuperscript{18}. Finally, the statutory scheme outlines the authority of both the State Health Director and local health directors regarding quarantine and isolation. These powers may be exercised only “when and so long as the public health is endangered, all other reasonable means for correcting the problem have been exhausted, and no less restrictive alternative exists.”

A person who violates any of the statutes in N.C.G.S. Chapter 130A (which includes all of the statutes summarized above) or the rules adopted by the Commission or a local board of health is guilty of a misdemeanor under N.C.G.S. 130A-25. Because the control measures are rules adopted by the commission, a violation of these rules could result in a misdemeanor charge. The law also states that any person who is imprisoned for violation of N.C.G.S. 130A-145 (isolation and quarantine) “shall not be released prior to the completion of the prison’s term of imprisonment unless and until a determination has been made by the District Court that release of the person would not create a danger to the public health.”\textsuperscript{19}

Proof of control measure violations is hard to obtain, as will be described at length below, but both the State and Local Health Directors have access to all of an individual’s medical records if they are determined to “pertain to the (i) diagnosis, treatment, or prevention of a communicable disease or communicable condition for a person infected, exposed, or reasonably suspected of being infected or exposed to such a

\begin{itemize}
\item \textsuperscript{17} N.C.G.S. 130A-148.
\item \textsuperscript{18} N.C.G.S. 130A-143.
\item \textsuperscript{19} N.C.G.S. 130A-25.
\end{itemize}
disease or condition, or (ii) the investigation of a known or reasonably suspected outbreak of a communicable disease or communicable condition.”  

When a local health director has proof that a person has violated the control measures, he or she has two options on how to proceed. First, the health director can choose to petition the District Attorney’s office to prosecute the individual who has allegedly violated the control measures immediately. Or, alternatively, the health director can issue an order requiring the person to refrain from activities prohibited by the in the future. While the individual has always been legally held to these standards, this “isolation order” essentially puts the individual on probation and is their final opportunity to change their behavior. Isolation orders can also include other requirements, such as substance abuse counseling, mental health counseling, or education and counseling sessions about HIV. If the individual violates the isolation order, the health director can then seek prosecution through the District Attorney’s office, pursuant to N.C.G.S. 130A-25.

Very few changes have been made to the control measures since they were implemented in 1988. A small alteration in 2005 stated that information obtained as part of the partner notification would no longer be destroyed within two years. In 2007, the requirement for pre-test counseling was eliminated; patients are now informed that an HIV test is being performed (often in conjunction with other standard blood work) and then given the opportunity to refuse testing. In addition, the regulations were changed to require that all pregnant women be offered HIV testing at both their first prenatal visit

20 N.C.G.S. 130A-144(b)  
21 10A NCAC 41A.0202, Control Measures – HIV, 12.
and again in their third trimester; furthermore if a woman’s HIV status is unknown at the
time of labor, an HIV test will be administered at that point. The 2007 changes are an
example of changes made in response to CDC recommendations, published in 2006.\(^{22}\)

The actual implementation of the control measures, including to what extent they
are enforced, is up to the local health director, who is given logistical support by the State
Health and Human Services and Disease Intervention Specialists. In North Carolina each
county has its own health department, so the County Health Directors are the legal
gatekeepers for the control measures. Because the control measures outline the legal
requirements for HIV positive individuals but do not go into detail regarding the
enforcement of these same requirements, a large part of this project was focused on
understanding how the implementation and enforcement of these statutes and regulations
occurs on the ground in those counties in which the interviewees work.

### 2.3 Public Policy Rationale for HIV Control Measures

In the late 1980’s when the North Carolina Control Measures were first drafted,
there was no effective treatment for HIV/AIDS.\(^{23}\) Essentially, when the control measures
were implemented, infecting another individual was the equivalent of sentencing them to
death. Furthermore, at that time, the scientific community had yet to conclusively
determine all of the channels through which HIV was transmitted. Therefore, all public
health schemes that were implemented to combat HIV at that time were focused

\(^{22}\) Bernard M. Branson, et al., Revised Recommendations for HIV Testing of Adults, Adolescents, and
Pregnant Women in Health-Care Settings, September 22, 2006,
http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5514a1.htm.
\(^{23}\) While AZT, the first pharmaceutical treatment invented for AIDS, was approved by the FDA in 1987, it
delayed the progress of the disease for only a limited period of time. Encyclopedia Britannica, “AZT,”
http://www.britannica.com/EBchecked/topic/46868/AZT.
exclusively on the prevention of transmission. The three control measure stipulations that are being focused on in this study are prime examples of these preventative efforts: condom use helps prevent transmission through sexual intercourse, disclosure of status may result in increased condom use or result in the uninfected individual choosing not to engage in risky behavior with the infected individual, and partner notification allows the state to identify other potentially HIV-infected individuals and attempt to prevent them from continuing the spread of the disease.

Today, effective treatment for HIV is available for the vast majority of HIV-infected individuals, and those who are receiving this treatment live for many years past their original diagnosis, sometimes just as long as they would have had they not contracted the disease.\textsuperscript{24} Because of an expansion of both the knowledge and methods of treatment for HIV, the public health community has prioritized other goals in addition to prevention. In light of the fact that there is effective treatment, the goal of getting HIV-positive individuals into care and onto effective treatment is a very high, if not the highest, priority.\textsuperscript{25} The most recent breakthrough in the medical community, the HIV Prevention Trial Network’s (HPTN) 052 Study, also confirmed that treatment is prevention, as individuals who are on successful treatment are much less likely to transmit the disease.


However, there is still no cure for HIV, treatment is very expensive, and both the disease and the treatment can have debilitating side effects. Therefore, states still have a public health interest in preventing the transmission of HIV. The questions remain, however: are the control measures changing behavior in such a way that results in a reduction in transmission of the disease? And how do the control measures interact with the goal of getting as many infected individuals as possible treated, into care, and on effective treatment?

When considering the answers to the questions, it is also important to recognize the tension between the goals of the public health community as a whole and individuals who are HIV-positive. The North Carolina Bar Association describes this tension as follows:

“The law strikes an uneasy balance between protecting the public health and the rights of people infected with HIV. For the broader community, there is an urgent need to stop the spread of the disease. For people with HIV, there are concerns about privacy, autonomy, and discrimination, along with a desire to live full and productive lives in the best possible health.”

That there is stigma surrounding HIV-positive individuals is a well-documented fact. HIV-positive individuals may face discrimination from their family, their community, their religious organization, their place of employment, and even their medical care providers. This stigma can be based on fear of catching the disease, judgment based on the ostensibly immoral ways through which the disease was

contracted, the sexual orientation of the HIV-positive individual, as well as other factors.\textsuperscript{29}

The very existence of HIV legislation validates this stigma. HIV control measures systemically regulate the actions of HIV-positive individuals, some of which would otherwise be perfectly legal. There is something inherently negative about needing to be “regulated.” Many control measures carry criminal sanctions; therefore an HIV-positive status can cause normally lawful activity (i.e.: sexual contact) to result in jail time for the individual who takes part in it. Therefore, these control measures further tie HIV to the negative, the “bad” and the criminal. HIV legislation “reinforces the stereotype that people living with HIV are immoral and dangerous criminals, rather than, like everyone else, people endowed with responsibility, dignity and human rights.”\textsuperscript{30} In any public policy discussion, these negative effects of HIV legislation must be balanced against the community’s valid priority of ceasing the spread of the disease.

\textsuperscript{29} Id.
3. Methodology

3.1 Study Design

The primary methodology employed in this study was qualitative, semi-structured interviews. This methodology allowed for the primary researcher to compare the statutory authority that allows for the promulgation of the control measures and what the language of the control measures legally requires with how those people who are implementing and enforcing these control measures interpret this language.

Qualitative data collection occurred in February and March of 2012 in Durham, Chapel Hill, and Raleigh, North Carolina. The protocol was developed by the primary researcher, with significant input from Professor Lynne Messer of the Duke Global Health Institute’s Center for Health Inequalities, who served as the project advisor. Background information was obtained through the Duke Legal Clinic and Duke Law School’s AIDS and the Law course.

The information gained from these interviews was supplemented with review of government documents as well as legal research. Multiple sources of data were needed because the manner in which the HIV control measures are implemented is not statutorily proscribed and the control measures are not always implemented in a manner that reflects either the statutory or administrative rule language. Additionally, data regarding the implementation of the HIV control measures in North Carolina is not tracked or monitored statewide.
3.2 Ethical Approval

Ethical approval for this study was obtained through the Duke University Graduate School Institutional Review Board. Each interview participant signed an informed consent form.\(^1\) A $5 Starbucks gift card was offered to each participant as a thank you for his or her time.

It was unfortunately not possible, given the study’s resource constraints, to gain ethical approval to interview HIV-positive patients about their perceptions of and experience with the HIV control measures. As the conclusion will elaborate, a study of the perceptions of patients would be very valuable in determining the control measure’s overall affect on the HIV-positive population in North Carolina.

3.3 Legal Research

Review of the relevant Legal Documents was conducted prior to the qualitative data gathering (interviews). The Statutes and Regulations reviewed were utilized to understand the legal framework of the control measures.

3.3.1 Sample Selection

All regulations in North Carolina include a “history note.”\(^2\) This note lists the statutory authority under which the regulations were promulgated, as well as the dates that the regulation came into affect, and the dates that any subsequent changes were implemented. All statutes listed in the control measures’ History Note (G.S. 130A-135; 130A-144; 130A-145; 130A-148(h)) were reviewed. Additionally, G.S. 130-25, which

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\(^1\) See Appendix C
\(^2\) See Appendix A
defines the punishment for the breach of any of the above listed Statues, was also included.

Subsequently the primary researcher attempted to identify the changes that had taken effect at each of the months listed. This proved to be quite challenging, due to the limited availability of past North Carolina regulatory text, both online and in print. The changes are supposed to be “proposed” (via the notice and comment process described above) in the North Carolina Register. Registers prior to the year 2000 are not electronically searchable. All relevant Registers from 1986 through 2000 were reviewed for mentions of the control measures, however only some of the changes included in the history note were found. All relevant Registers from 2000 onwards were electronically searched for the inclusion of the text “control measure*,” again, however, only some of the listed changes included in the history note were found. The regulation text that could be located in the Register was reviewed for any significant changes.

3.3.2 Protocol and Analysis

The Statutes were considered collectively, in order to understand their interaction with one another and the manner in which they established a legal foundation for the North Carolina Control Measures. The statutes were then summarized in a manner that explained how they established the control measures. Additionally, the manner in which the establishing statutes instructed the Commission regarding what must be included in the control measures was outlined.

3 This is likely because there are some exceptions to the notice and comment requirement, typically regarding very small, or merely textual, changes made to any given rule. Therefore, those changes that could not be identified were likely not significant.
3.4 Qualitative Data Collection

3.4.1 Population

Three categories of individuals were interviewed: infectious disease physicians whose clinical work is primarily with HIV-positive individuals, government officials and employees involved with the implementation and enforcement of the control measures, and other individuals who provide care to HIV-positive individuals or who have policy experience with HIV/AIDS in North Carolina.

3.4.1.1 Infectious Disease Physicians

Three physician interviews were conducted with infectious disease doctors at the Duke University Medical Center. Interviews with physicians were conducted because of the roles that the control measures assign to them. Under the control measures, an HIV-infected individual’s attending physician is required to

(a) “give the control measures … of this Rule to infected patients, [and]

(b) if the attending physician knows the identity of the spouse of an HIV-infected patient and has not, with the consent of the infected patient, notified and counseled the spouse, the physician shall list the spouse on a form provided by the Division of Public Health and shall mail the form to the Division. The Division shall undertake to counsel the spouse. The attending physician's responsibility to notify exposed and potentially exposed persons is satisfied by fulfilling the requirements of Sub-Items (2)(a) and (b) of this Rule…”

Moreover, the attending physician “shall notify the local health director when the physician, in good faith, has reasonable cause to suspect a patient infected with HIV is not following or cannot follow control measures and is thereby causing a significant risk

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4 10A NCAC 41A .0202, “Control Measures – HIV.”
of transmission.”⁵ Therefore, the control measures create affirmative legal duties for physicians, in addition to HIV-infected individuals. The physician interviews explored the ways in which these legal responsibilities are actually implemented, and in what manner these legal responsibilities interact with the physician’s ability to provide the best care for their patient.

### 3.4.1.2 Government Officials and Employees

Five Government officials and employees were interviewed: The Medical Director of the North Carolina HIV/STD Prevention and Control Branch⁶, a County Health Director, one State-employed Disease Intervention Specialist, a Field Services Manager of the State’s Communicable Disease Branch who oversees the regional field offices of the Disease Intervention Specialists, and a Durham County Medical Director. Interviews with government officials were conducted because of their role in the implementation and enforcement of the control measures.

The State employees, overseen by the State Communicable Disease Director, and managed by the Field Services Manager, are the face of the control measures. They conduct interviews with all newly diagnosed individuals in North Carolina soon after their diagnosis is reported and present the control measures to these individuals at that time.

The County Health Officials are the gatekeepers of the control measures. The statutory scheme under which the control measures were established charge these

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⁵ Id.
⁶ The State Communicable Disease Director is also an Infectious Disease physician and is employed by the University of North Carolina, therefore his experience with the control measures, and opinions of them, also includes perceptions from this experience.
individuals with the responsibility of investigating and, if necessary, prosecuting those found to be in breach of the control measures.

3.4.1.3 Other Care Providers and Policy Experts

Three other individuals were interviewed. The Executive Director of an AIDS Organization, a policy expert who is currently employed with the Duke Global Health Institute, and a post-test counselor employed by an AIDS Organization.

The post-test counselor was interviewed because she performs similar functions as the Disease Intervention Specialist in terms of instructing newly diagnosed HIV-positive individuals on the control measures. The policy expert has experience training HIV-positive peer educators, who in turn educate newly diagnosed patients about the control measures. The Executive Director of the AIDS Organization manages an organization that provides care for HIV-positive individuals, has assisted in developing DIS training and participated in training DIS, and is heavily involved with statewide policy discussions.

3.4.2 Sample Selection

All study participants were required to be over 18. Physician participants were included if they had been working primarily with HIV patients for more than two years in North Carolina. County and State Government employees, as well as other key informant interviewees, were included if they had been in their position, or in a similar role in North Carolina, for at least two years.
3.4.3 Sample Recruitment

Study participants were recruited via email (see Appendix D). Physician emails were acquired through the Duke University Medical Center website. Government Official’s emails were obtained through either the state or county government websites, or through calling the state or county government office where the individual is employed. Other interviewees’ emails were also obtained from their employer’s websites.

3.4.4 Protocol

The interviews were conducted either in person or over the phone. All interviews were electronically recorded except for three, one due to the fact that the interviewee did not wish for the conversation to be recorded because it was occurring via phone and two due to technical difficulties. Extensive notes were taken for these three interviews. The interviews followed a semi-structured interview guide that included both main questions and subsequent prompts. The interviews were informal in nature and the primary researcher attempted to ensure that they were conversational in tone. The interview guides were updated as the research progressed and certain themes or gaps in knowledge emerged. A $5 Starbucks gift card was offered to each of the participants as a thank you.

3.4.5 Instrument

The interview guides were developed with input from Professor Lynne Messer, the project advisor. The DIS interview guide was piloted with a disease intervention specialist who was not subsequently a participant in the study.

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7 See Appendix E.
3.4.6 Data Analysis

The interviews were fully transcribed by the researcher. The transcripts were then coded thematically based on the context of the responses. Response categories were combined across the interviews in order to determine respondent themes. The primary researcher expected the themes to be organized around the three control measures considered (status disclosure, condom use, and partner notification), however, other unexpected themes arose throughout the course of the interviews, such as 052’s importance, and the effect the Internet has had on HIV prevention. In addition, implementation and enforcement procedures proved to be much more complicated and less standardized than expected prior to the interviews.
4. Results and Discussion

Eleven total interviews were completed. All interviewees work in Durham, Wake, and Orange Counties. Two of the interviewees are state employees who have responsibilities statewide. Four of the interviewees were female, seven were male.

Because of the exploratory and qualitative nature of this policy study, the results and the literature review are presented categorically below. Many of these themes were identified a priori in the interview guide, but some arose in multiple interviews despite not being explicitly included in the original questions. The qualitative results and the legal review results are combined under each theme section. This manner of presentation was utilized in order to maximize the clarity of the information presented.

4.1 Interviewee familiarity with the control measures

One theme that arose relatively early on in the interviewing process was a vast difference in familiarity with the control measures on the part of those interviewed. While the testing counselor and the Disease Intervention Specialist (DIS) were very familiar with the text of the control measures, none of the physicians remembered receiving specific training regarding them.

At the beginning of one of the physician interviews, the interviewer was asked to clarify exactly what was meant by the control measures. Another physician indicated that it had been at least five years since he had reviewed the text of the control measures. Despite the fact that the control measures create legal duties for physicians the providers interviewed were only generally aware of their contents and were often fuzzy on the specific details of the regulations.
Physician: “Well, why don’t you tell me what you mean when you say the control measures? I’m not 100% sure what that term means.”

Physician: “I think there’s an awareness of what represents the bounds of acceptable behaviors. Certainly things like reporting to the state and so on, we do adhere to those requirements. But the more problematic, sort of behavioral management issues, I don’t think we’ve ever, that I know of, explicitly discussed them.”

The government officials, as well as the policy expert and AIDS Organization Executive Director, all indicated that they had reviewed the control measures at some point in the last year or so. At the time of the interview, the DIS stated that he had reviewed the control measures with a newly diagnosed individual within the previous week. The testing counselor had reviewed them earlier in the day she was interviewed and stated that she reads them to patients almost every day she is at work.

After early experiences with interviewees being unfamiliar with the control measures, the interviewer began subsequent interviews with a query about the interviewee’s familiarity with the control measures; this was not originally expected to be a term that would need clarification.

4.2 Implementation of the control measures

Disease Intervention Specialists are, for all intents and purposes, the face of the control measures in North Carolina. Every newly diagnosed patient in the state of North Carolina, if they can be located, is interviewed by a DIS. During this interview, the patient is provided with a copy of the control measures and asked to sign them. These signed copies are stored by the state.

The DIS Supervisor interviewed indicated that there is relatively high turnover rate in this position and that people typically remain in the position for just two to three
years. However, one of the DIS interviewed has been in the position for over a decade.

DIS hired by the State have at least a bachelor’s degree, typically in a health or behavioral science field.

The DIS Field Supervisor explained that all DIS go through three months of training. Over these three months they complete federal standardized modules that cover topics from the specifics of the overseen disease (HIV, Syphilis, Gonorrhea, Chlamydia) as well as various details about the position. These modules are taken on the DIS’s own timeline and are completed via self-study. After each module the DIS-trainee must pass a test on the material. During this time the trainee is also shadowing other DIS in the field. The DIS trainee also receives phlebotomy training (so that he or she can draw blood for testing). Finally, all DIS go through a two week course called FDI – Fundamentals of Disease Intervention. North Carolina’s FDI is patterned off of a similar CDC program. This course covers interviewing skills, safety, and sensitivity. According to one interviewee, approximately two to three days (out of ten) are spent on the HIV Control Measures.¹ Finally, the DIS trainee does one interview of a real patient while being observed by a supervisor.²

When a DIS receives information about a new case, the next step is to gain all the information possible about the individual. This information is obtained through a search of medical records,³ a search of the court calendar website for any information regarding pending criminal charges, and an investigation of less official sites, such as Facebook.

¹ The control measures for syphilis and other communicable diseases are also reviewed during DIS training.
² The training is outlined in detail in the DIS Training Documents in Appendix F.
³ Under N.C.G.S. 130A-144(b).
The DIS internal records are reviewed for past STD (non-HIV) infection, and if there is an indication that the individual has been to a major hospital locally, the DIS will attempt to obtain those records as well.

Once this information gathering is completed the DIS attempts to reach the individual via phone. If there is no response, a home visit is made and a form letter is left at the property. This letter is stamped personal, or confidential, and requests that the person named contact the DIS about a personal or private health matter. If there is no response to the letter, the DIS will attempt to intercept the person at the individual’s next medical appointment. As a final measure, the DIS will attempt to locate the individual at his or her workplace, although the DIS interviewed stated “we hate to do that, but sometimes that’s all we have.”

When the DIS successfully arranges the meeting, the DIS first identifies himself or herself and then asks the person to verify his or her identity (through confirmation of their date of birth or similar information). The DIS who was interviewed stated that he preferred to consider the patients his “clients” and that his style “has always been conversational, [and he just goes] wherever the client goes,” while keeping a mental checklist of the questions that he needs to get answered.

During this initial interview, the DIS provides the control measures to the newly diagnosed individual. The client’s signature is obtained, indicating that the individual was, indeed, informed of these rules. If the individual refuses to sign, this refusal is documented. The DIS also answers any questions that the individual might have regarding the control measures. After providing the client with these regulations, the DIS
completes a contact-tracing interview. Partner notification will be discussed at length below, but essentially the DIS attempts to gather names of sexual partners from the newly diagnosed individual. Those named are then notified, either by the index patient or the DIS, that they may have been exposed to a sexually transmitted disease.

4.3 Enforcement of the control measures

As was mentioned above, the local health directors are the gatekeepers of the control measures. It is these individuals who determine when and to what extent the control measures are enforced. North Carolina has 100 counties and 85 health departments.\(^4\) Seventy-nine of the health departments are for individual counties and six of the health departments span multiple counties. Each of these departments has a local health director. The local health directors are described as the “the front lines of communicable disease surveillance, response and control in our communities.”\(^5\)

The County Health Director described the DIS as “the state people,” which is an accurate observation, as the vast majority of North Carolina-based DIS are state employees. The DIS supervisor referred to the DIS as the “arm” of the county, and as being “under the jurisdiction” of the county.\(^6\) All interviewees familiar with the enforcement emphasized that the County Health Director is the legal authority when it comes to the control measures.

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\(^6\) According to the DIS Field Supervisor, Mecklenburg, Guilford, Wake, Pitt, and Cumberland Counties have their own, county-employed DIS. As stated above, all other DIS are state employees.
4.3.1 Flow of information regarding control measure violation evidence

Despite having interviewed four individuals on this topic, it is unclear how the information that serves as evidence of a breach moves between the State Health and Human Services (HHS) and the County Health Departments. However, it was clear that even if the State is the organization that becomes aware of the breach, that information is relayed to the appropriate county and the county takes control of the situation.

There are four types of information that can prompt an investigation of a control measure violation: (1) an HIV-positive person becoming infected with an incident STD or STI that is reportable to the state, such as syphilis; (2) an HIV-positive person being reported by a newly diagnosed individual in their partner notification process; (3) a physician contacting either the State or the County Health Department to express concerns about a patient’s behavior; and (4) a third party contacting either the State or County Health Department to report on an HIV-positive individual’s behavior that is in violation of the control measures.

The County Medical Director cited an incident STD/STI infection in an HIV-positive individual as the strongest type of evidence. Typically episodes of reportable STD/STI infections are utilized in this fashion, as these are the only ones of which the health department would become aware. STDs that are reportable under North Carolina Law include both gonorrhea and syphilis. It is also possible that an HIV-positive person will be named by a newly diagnosed individual through partner notification. As part of the interview process, the DIS questions the newly diagnosed individual whether anyone

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7 10A NCAC 41A .0101, “Reportable Diseases and Conditions.”
that the individual named as a sexual partner had disclosed that they were HIV-positive. If an HIV-positive person is named as a sexual partner, but the individual does not report being informed that any of his or her partners were HIV-positive, this can be used as evidence that the named partner was violating control measures. Finally, health departments receive reports from both physicians and third parties who are concerned about an HIV-positive individual’s risky behavior that is in breach of the control measures. Typically, the health director noted, these reports are made about people that the health department is already aware of for just this reason.

Obtaining sufficient documentation to prosecute is challenging,\(^8\) due to the fact that the authorities struggle to enforce laws regarding what occurs in the private sphere, such as sexual relationships. The County Health Director emphasized that it’s necessary to be “incredibly systematic” about it. Third party reports are particularly problematic:

County Health Director: “Oftentimes you get somebody who shows up at your office and says, I had sex with Joey, and Susie says he’s HIV+ and he didn’t tell me. That doesn’t hold up in court. The only [cases] that we would deal with [legally] where I was health director is if we had empirical proof that Joey, who we knew was HIV+, was having unprotected sex because [he was diagnosed with another] STD. We never took a situation to court where Susie claims that Joey’s doing this but Joey never shows up with any sort of STD and Susie never shows up pregnant.”

The County Medical Director indicated that it sometimes difficult to provide sufficient evidence to prove a breach of the control measures, and often, for cases that are legally pursued, the health department attempts to find a witness who will testify that they had

\(^8\) The standard of evidence for investigating a control measure violation, and subsequently issuing an isolation order, is quite low, as it is basically at the discretion of the local health director. If the director wishes to petition the District Attorney’s office to prosecute the individual, however, the evidentiary bar is higher; prosecution would not likely occur based on only one individual’s word, but would instead require scientific confirmation of an incident infection, or multiple partner reports.
sexual relations with the HIV-infected individual that were in violation of the control measures.

While it seems that both North Carolina and its County Health Departments are collecting a considerable amount of health information, it is unclear how this information is transmitted from one level to another. While there is a Central Surveillance Unit in Raleigh, the DIS Field Supervisor noted that there is no central database that stores information on every individual. Laboratories who run these types of tests report to the State about any of the statutorily defined reportable conditions. The county sometimes receives such information directly as well, particularly if the individual is being tested at the county health clinic. The county also may receive a report from a DIS outlining data that indicates a violation may have occurred. However, the county does not automatically receive all STD data, or the information that the DIS collect in their interviews. The DIS seem only to report such information to the county if they are concerned about a violation, and there also seems to be some discretion on their part, as the Field manager stated that just because someone tests positive for a disease does not mean that they are in violation of the control measures (gonorrhea, for example, can be spread in ways that are not defined as sexual intercourse).

4.3.2 Awareness on the part of HIV-positive individuals

It is also unclear to what extent patients are aware that an incident STD infection can trigger control measures violations. One physician thought the following:

Physician: “They’re pretty aware. There’s a recommendation to test for syphilis annually in our HIV-infected patients, and typically before I do that I’ll say, it’s ok if I test you for syphilis today, right? And if I have some suspicion that it’s gonna be positive or whatever, I will often say,
you know that this gets reported to the health department, and I’ve had
some who have actually refused…”

The DIS indicated that while the majority of people ask him about how the
government could possibly know if they break control measures, he only “takes it as far
as they want to go.” He stated that he is honest in his response, and tells them that the
government might not find out. He follows up, however, with the idea that:

DIS: “The other possibility is that one of your partners, or your future
partners gives your name to us [in a partner notification interview]. And
whether you infected them or not, that could happen. You might think
that, oh, everything’s roses and that person would never do that to me, but
as soon as you break up or you cross them or vice-versa, they’ll spill their
guts about you…”

The DIS was also asked if he also went into detail regarding incident infections
being reported to the health department, and it seems that he only does so if the
individual brings it up first.

4.3.3 Enforcement procedures

The County Health Director and the County Medical Director both spoke to the
way in which the control measures are enforced. While the enforcement does vary from
county to county, the pattern of response by the County Health Director interviewed goes
as follows:

1) If an individual is suspected of violating control measures, he or she is asked to come
into the health department for a meeting. During this meeting, he or she receives
follow-up counseling on the control measures by a Communicable Disease Nurse.
This process is meant to “make sure they truly understand that they have a
communicable disease and understand what they shouldn’t do that might put others at
risk.” Alternatively, or in addition to this meeting, a DIS may also be dispatched to their home to give them similar counseling.

2) If there is evidence that this individual is continuing to breach control measures subsequent to follow-up counseling, a team meeting is called. This meeting typically involves the health director, the DIS who originally provided the patient with the control measures (and, if applicable, the DIS who provided repeated counseling), the communicable disease nurse who provided follow-up counseling, and anyone else who is managing the individuals’ care, such as a case manager. In this meeting the health director attempts to determine “What’s this person’s button? What can I say to this person to get them to pay attention to what I need them to do?”

   County Health Director: “In one instance it was the guy’s job, he just absolutely took a lot of pride in his job, and for him the worst possible outcome would be the health director showing up at his place of work and asking to speak with him”

3) Subsequent to this team meeting, the health director holds a meeting with the individual himself, in order to emphasize the potential consequences that will result from the individual continuing to behave in a way that violates control measures. The health director saw this meeting as the individuals’ last chance: “The next step is that I will talk with the DA and we will issue a warrant for your arrest.”

   County Health Director: “For the guy who was real motivated about work, I said and you know, the deputies will come to your work, and they will serve you with that arrest warrant. And he said, I don’t want you to do that, I don’t want you to do that, I promise, I’ll use a condom every time, I’ll tell people I’m HIV+, I’ll do whatever you want, just don’t come to my work. And I never saw him again.”
4) Finally, if it is clear that these types of interventions are not changing the individual’s behavior, the Health Director will go to the District Attorney and ask them to petition a judge for an arrest warrant for violation of control measures.

Both county employees who were interviewed emphasized that the people who truly do not respond to these interventions typically have additional roadblocks, such as drug addiction or mental health problems. For example, the County Health Director dealt with an HIV-infected woman who was “prostituting herself to raise money to buy the drugs she was addicted to, and there was nothing I could have said to her that was going to change that behavior.” Ultimately, an arrest warrant was issued, but the Health Director worked with the judge to craft a probation order that suited the situation. Under the terms of her probation, the woman was required to attend a 90-day inpatient drug treatment program. Additionally, she could not be arrested for anything related to drugs or anything related to prostitution, and she was required to take an STD test at the health department every six months. Subsequent to this legal intervention, the woman “got clean, moved back in with her mother and three children.” The woman also passed away a few years later, from AIDS-related complications. The Health Director was thankful that she could solve the problem without incarcerating the woman so that she wasn’t kept away from her family for her last years of life. Both County Health Officials emphasized that seeking legal action was a last resort, and that such steps were only taken after all other plans of action had been exhausted.
4.4 Issues with Enforcement

Despite the fact that there are very few people prosecuted under the control measure every year, some interviewees still expressed concern with the potentially inconsistent application of control measure enforcement due to the fact that it is county-by-county. The Executive Director of the AIDS Organization noted “If you have a good health director, you’re good, and if you have a bad health director, you’re not good.” The nuances of implementation that were discussed by all the interviewees do indicate that the enforcing health director must have a high level of sensitivity to the nuances of HIV and its affect on individuals. While the County Officials interviewed for this project certainly communicated a high level of public health knowledge and skill, it cannot be assumed that this is the case for all local health directors across the state. Because of the significant level of authority that these individuals have, there is certainly room for concern.⁹

This concern is exacerbated because of the fact that HIV-positive individuals are typically already part of vulnerable populations, even before their HIV diagnosis. During the beginning of the epidemic, the majority of those who were infected were gay men and intravenous drug users, two populations who were (and continue to be) marginalized regardless of HIV status.¹⁰ The disease has continued to disproportionately affect already-

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⁹ The County Health Director continues to have discretion after an HIV-positive person is incarcerated for control measure violations. Under N.C.G.S. 130A-25, an individual incarcerated under this statute cannot be released “prior to the completion of the person's term of imprisonment unless and until a determination has been made by the District Court that release of the person would not create a danger to the public health.” This determination must be made in consultation with the local health director. N.C.G.S. 130A-25. ¹⁰ Avert, “HIV & AIDS Stigma and Discrimination,” http://www.avert.org/hiv-aids-stigma.htm.
marginalized populations, namely gay men\textsuperscript{11} and African Americans\textsuperscript{12}. These are also populations who have historically been restricted through criminal law and the criminal justice system in this country. Just over 50 years ago there were still segregation laws throughout this country that restricted the actions of African Americans. Until 2003, sodomy was still a criminal act in 13 states. Although the Supreme Court found such laws unconstitutional,\textsuperscript{13} North Carolina’s sodomy law remains on the books and was used to charge a man just last year.\textsuperscript{14} State governments across the U.S. have consistently used criminal legislation to restrict the activities of already marginalized populations, and as a result, maintain the power structures around which our society is built; the criminalization of HIV is no different. Finally, while criminalizing HIV results in a heavier legal burden for already marginalized populations due to the fact that incidence rates are higher in these populations, there is also a concern that the application of the statutes will be unfair or arbitrary and that prosecutions will be more commonly directed at those who are socially and/or economically marginalized.\textsuperscript{15}

The State Medical Director expressed these exact concerns without solicitation:

“[The control measures are] totally flawed, and in my mind it’s arbitrary, and that’s the worst case scenario to have a flawed, arbitrary rule that can actually result in inhibiting the things that we’re trying to do in public health.”

\textsuperscript{13} Lawrence v. Texas, 539 U.S. 558 (2003).
He also noted that, because these prosecutions (or the preceding steps) are not tracked statewide, there is significant potential for unequal enforcement. But, it is hard to say whether or not such a trend is occurring. His hunch

“is that race and sexual identification probably impact what decision is made about what to do with someone. Meaning that, I think if you’re an MSM you’re more likely to get a misdemeanor charge or get pushed towards criminalization than if you’re a white heterosexual female.”

From another perspective, the Executive Director, was concerned with how few prosecutions there are.

“It frightens me when I see the number of people who break control measures repeatedly… in Wake County they intervene like twelve times before they even think about [legal action]… and this guy\textsuperscript{16} had broken control measures off the charts. It wasn’t one or two, there were probably 100 that were reported.”

It is clear from the information gathered about enforcement that there is significant room for unequal enforcement. Whether this inequality is (or could be) along racial or sexual identity lines is unclear because of the lack of data on these types of prosecutions. Many concerns were raised by interviewees regarding whether or not the control measures are beneficial to the public health. The questionable effectiveness of the control measures may be one of the reasons that legal action against control measures violators is taken so rarely. The County Health Director interviewed stated that she is “actually more likely than most to prosecute control measure violators.” Despite this claim, however, in 15 years as County Health Director she has issued isolation orders to only 12 individuals and taken individuals to court on just two occasions.

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\textsuperscript{16} The interviewee was referring to a specific case in which an individual was prosecuted under the control measures, which will be discussed in further detail below.
4.5 Criminalization

Overall, criminal law discourages negative behavior, rather than actively encouraging positive behavior. For example, the control measures discourage unprotected sex by HIV-positive individuals (by criminalizing it) but treat HIV-positive individuals who have no sex at all and those who have protected sex equally. This is somewhat incongruous with the fact that much of the literature regarding effective HIV treatment states that behavioral interventions that are based on positive acts, rather than prohibitions or limitations, are more successful.\textsuperscript{17}

Behavior change is key if the epidemic is to be halted. As noted above, there is currently no cure for HIV and at least 20% of Americans who are infected are unaware of their status.\textsuperscript{18} At least a portion of these individuals is engaging in behavior that puts others at risk for infection as well. Research indicates that behavioral interventions can reduce HIV infection and “in all cases in which national HIV epidemics have reversed, broad-based behavior changes were central to success.”\textsuperscript{19} The question is, however, does the criminalization of certain types of behavior through the control measures effectively alter the behavior of HIV+ individuals?

As noted above, the control measures are included in the administrative public health statutes rather than the State’s Criminal Code, but failing to adhere to the measures

can result in criminal punishments, including considerable prison sentences (up to two years). Therefore, the control measures are essentially criminal law, and share the three typical objectives of most criminal law: incapacitation, promotion of normative behavior, and deterrence:

“Incapacitation prevents those who have acted criminally in the past from acting in a similar manner by removing them from the community. Promoting normative behavior encourages individuals to act within the confines of the law because they believe it is the right thing to do. Deterrence attempts to discourage individuals from engaging in criminal activity by enforcing grave consequences for such behavior.”

The control measures can cause individuals who repeatedly breach the regulations to be incarcerated and thus kept away from the general population whom they are allegedly putting at risk with their behavior. The control measures also represent the North Carolina government’s stance on what the “normative behavior” for those with HIV should be, and encourage individuals to behave in this way. Finally, the control measures discourage failing to behave in the prescribed ways by enforcing punitive consequences against those who do not adhere to the control measures. While this breakdown of purposes was not explicitly communicated by any of the interviewees, each overarching “goal” did arise multiple times.

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20 Since the beginning of the HIV epidemic, states across the country have implemented legislation that criminalizes certain behavior of HIV-positive individuals in order to deter and punish transmission of the disease. There are two main ways in which States have criminalized the activities of HIV-positive individuals: felony laws that criminalize transmission (intentional or not) of the virus, and control measures, which are public health measures that may have criminal sanctions if broken. North Carolina does not have any HIV-specific felony laws, but it does have HIV Control Measures that, if broken, can result in a misdemeanor, which in turn carries a criminal penalty of up to two years in jail.

4.5.1 Incarceration

While almost all the interviewees expressed how rarely individuals are prosecuted under the control measures, people have still spent time in prison for failing to follow them. Sex is illegal in all U.S. prisons, and condoms are unavailable in nearly all.\textsuperscript{22} Despite this, however, many studies have shown that risky sexual behavior occurs regularly within the prison system.\textsuperscript{23} While both the World Health Organization and the United Nations Program on HIV/AIDS “have recommended for more than a decade that condoms be made available to prisoners,” there has been little movement on the part of the U.S. penitentiary system to make this shift.\textsuperscript{24}

In 2004, 1.8\% of all prison inmates in the United States were HIV-positive. (The disease was much more concentrated in some geographic areas than others. In the same year, New York prisons had an HIV prevalence rate of 7\%).\textsuperscript{25} The activities that result in prison sentences (particularly drug use) overlap considerably with the risk factors that cause a higher risk of HIV infection. It is not surprising, therefore, that “it has been estimated that 25\% of all HIV-infected persons in the United States spend time in a correctional facility.”\textsuperscript{26}

It has been argued that “many U.S. [prison] officials adopt a ‘just deserts’ philosophy, viewing infections as the consequences of breaking prison rules.”\textsuperscript{27}

\begin{flushleft}\textsuperscript{22} S. Okie, “Sex, Drugs, Prisons, and HIV,” 356 New England Journal of Medicine (Jan. 2007) pg. 105. \\
\textsuperscript{24} S. Okie, (pg. 105), supra note 22. \\
\textsuperscript{25} Id., pg. 106. \\
\textsuperscript{26} Id., pg. 108. \\
\textsuperscript{27} Id., pg. 108. \end{flushleft}
Considering this mentality, as well as the high levels of risky sexual behavior and drug use that take place in prisons, and the lack of condoms or needle exchange programs, it seems that it would be very detrimental to send an HIV-positive individual who has breached HIV legislation into this environment.

Additionally, this seems to seriously undermine at least one purpose of the incarceration, which is to protect “society” from HIV infection (and, necessarily, from HIV-positive individuals who could cause such infection). While many people may not consider prisoners active members of society, those who become infected while in jail (even possibly as a result of interaction with HIV-positive individual who is in prison due to his infection and subsequent behavior in the first place) will likely reenter society at some point. Once they do, they will not only be part of a contingency that is already seriously disadvantaged (previously convicted felons) but they will also have the new burden of an HIV-positive status, and they will be regulated by their state’s HIV legislation, completing the detrimental cycle.

Concern over prison sentences was expressed by the State Medical Director, who noted that while the individual will ultimately be released from prison, he or she will still have HIV. He compared this situation with that of individuals who are incarcerated because of breaching control measures for another regulated disease, Tuberculosis, as it is possible to cure TB.

State Medical Director: “For TB we keep them in there until they’re done with their meds, but what can you do with HIV? It’s never going to go away… What’s the logical conclusion of all this stuff? … You’re going to lock someone up until when? Until they’re no longer infectious? That means life long.”
While these are valid concerns, the AIDS Organization Director supported the State having the power to punish someone for breaching control measures. He spoke at length about a particular case in which a man was found to have repeatedly broken control measures, seemingly maliciously.

“[The individual who was incarcerated for breaking control measures] was doing really bad things. I don’t think his name should be all over the Internet, but if he was a murderer, or a child molester, his name would be all over the Internet… he has a weapon of violence and harm. If he was going around beating up people, his name would be all over the Internet. And that’s what he’s doing, he’s going around with malice and forethought, putting other people in danger…”

Essentially, this AIDS Organization Director wants the State to be able to prosecute those who intentionally transmit the disease to others, or who use their HIV as a “weapon.” Many states have grappled with this very issue, and many HIV-specific felony laws are in existence as a result. North Carolina does not have such a felony law, but it does have a criminal code that allows prosecution for both battery and assault. The individual above could potentially have been charged under either of these theories. The State Medical Director echoed this sentiment:

“There are plenty of rules on the books currently that if someone intentionally infects someone else for HIV, they can be taken to court, they can be locked up, they can be sued, they can be charged for civil damages at least, if not criminal damages if they can show intent.”

Intent, however, can be issue in this type of case, because while an individual may intend to have sex, and perhaps intend to have unprotected sex, proving that he or she intended to transmit the disease would potentially be a challenge.
4.5.2 Encourage Normative Behavior

Through many of the interviews, the theme arose that people who do follow the control measures do it less for legal reasons and more because they believe it is the right thing to do.

Interviewer: “What do you think their motivations are for following [the control measure] recommendations?”
Physician: “I think the vast majority of them don’t want to infect a loved one…”

Physician: “I do think most people don’t want this to happen to someone they care enough about to be having sex with”

Similarly, both physicians and DIS attempted to present the control measure regulations as less something that people must do, and more as something people should do, to protect the health of themselves and those with whom they have sex.

Physician: “I don’t think it benefits them or changes their behavior to try to couch it in terms of the legal ramifications of their circumstances.”

Policy Expert: “In training [peer educators] don’t stress the legal end of it, but the responsibility end of it.”

Another theme that arose with equal frequency was the idea that sexual behavior is not always the most rational of actions and that even those individuals who attempt to make safe sex decisions (and thereby follow the control measures) struggle to do so “in the moment.” A study released earlier this year attempted to explore whether there were any causal links between an individual’s intentions to adopt seroadaptive behaviors and their subsequent success at doing so.28 The study surveyed men about their intentions

regarding safe sex practices and followed up with them over the course of a year to determine how well each individual fulfilled these intentions. Of the HIV-positive men surveyed who intended to utilize condoms 100% of the time when having anal sex, only 20% ultimately did so. While that particular study was limited to a specific community (MSM in San Francisco), the physicians interviewed for this study seemed to think that the difficulty that people have with making responsible sexual decisions is universal.

Physician: “I’m old enough, I’m experienced enough to know that people’s sexual behaviors are not always governed by rational thought. And that I think it would be exceptional if a person 100% of the time did things exactly right, so I get it.”

Physician: “People do things with their sexual lives that defy rational thought, and even logical discussions of behaviors when it comes down to ‘this is an opportunity for me to have sex,’ they often don’t enter into the decision about yes I’m going to proceed, or no, I don’t have a condom, I’m going to pass…”

Essentially, the interviewees expressed the idea that even those people who have the best of intentions (such as following control measures in all situations) might fail purely because of the irrationality of sexual behavior decision-making. This sentiment was typically expressed in conjunction with the idea that the government cannot police sexual behavior. Despite the fact that the interviewees generally stated that existence of the control measures does not successfully influence people’s attempts to stay within the bounds of expected behavior, the policy expert did note that the control measures do “call people’s attention to the measures they should be taken to prevent transmission to others.”
4.5.3 Deterrence

Finally, criminal law attempts to deter illegal behavior by defining punitive consequences. The control measures are meant to deter individuals who are not swayed by the normative behavior motivations discussed above from behaving in a certain way by creating a threat of punishment. The interviewees almost unanimously agreed that the control measures do not fulfill this goal. This is partially because people believe that they will not get caught, as it is difficult to imagine how the government would come to know about breaches of the control measures that happen in private.

Physician: “Even like, oh I heard Jimmy got thrown in jail for doing this, they think, well, who’s going to know? And what’s going to happen? So I don’t think anybody, or many people, view the threat of legal intervention as something that influences their decision to have sex at any one time or another.”

Additionally, most of the interviewees agreed that there is a (arguably accurate) sense that this is not a law that is enforced very often.

Interviewer: “Do you think the threat of legal ramification affect people’s behavior?”
Physician: “Not very much. Probably because there aren’t examples, I think if there were two stories a year about somebody got put in jail for putting people at risk, that might be more compelling.”

Physician: “I don’t think the legal part of it, because… it may exist on statutes, but it’s not enforced, it’s kind of a paper tiger, that’s not a reason people worry. I think they would be more worried about, ‘if I told him or I told her, they would kill me.’ Usually figuratively, but sometimes maybe not just figuratively, I think that’s more of an issue than being arrested and put into jail.”

Interviewer: “Do you think legal ramifications change people’s behaviors?”
Policy Expert: “Honestly, I don’t, I think that the law is not really enforced… Maybe if the law was more enforced it would have more of an affect on people’s behaviors.”

DIS: “The reality is that the law isn’t really upheld, in extreme cases where there’s obvious proof that someone has violated nine separate occasions [it might be upheld]… The cases that are upheld are the ones where the quote unquote ‘victims’ go to a hearing or a court of law, because the DA says I’m not going to do anything unless I have a witness that says this person didn’t insist on condom use or they didn’t disclose their status… Most health directors have to worry about the flu, as opposed to HIV, and the DA has to worry about murder investigations as opposed to HIV.”

There is also the possibility that, instead of deterring negative behavior, this criminalization scheme is deterring positive actions. Partner notification will be discussed at length below, but the DIS interviewed indicated that individuals often do not want to identify partners because they do not want to get those individuals in trouble. After they have received the control measures, some newly diagnosed individuals understand that, if they were to name a partner who has previously been tested positive, this information could be used against that person. Despite the fact that this partner could have potentially infected them with the virus, the DIS believes that “98% of the time, they don’t want this person to get in trouble.”

4.5.4 Overall Effectiveness

The overall effectiveness of the control measures on all types of behavior was questioned by all of the individuals who were interviewed.

Physician: “Are these control measures helping and making a difference? Honestly, I don’t think so, personally. And I don’t think that the STD reporting data would suggest that they’re making a big difference.”

State Medical Director: “We’re seeing lots of transmission from known positives, who have gotten their information and they continue to go out
and have behaviors that lead to transmission. So even with the control measures the way they are, they’re not effective.”

4.6 Partner notification services

Partner notification was first used in the United States in the 1930’s to combat gonorrhea and syphilis. “The rationale behind partner notification is that it allows identification, treatment, and education of individuals who have been exposed to a communicable disease, preventing the spread of the disease and helping people understand how to avoid future infection.”29 After penicillin’s invention in the early 20th century, both gonorrhea and syphilis could be cured, which meant that if partners were notified, a test for exposure could be conducted, treatment could be implemented, and the chain of infection could be stopped.30 Partner notification, when utilized in the context of HIV arena, has similar policy goals; however, because there is no cure, the chain of infection is not as easy to stop. An ACLU article from 1998 that opposes partner notification claims that it is not an effective policy in the HIV context because

- There is no “drug therapy to cure HIV or prevent transmission,
- [HIV has] a long incubation period which makes it difficult for patients to name and locate past partners,
- [And there are] serious concerns about confidentiality and social stigma.”31

Regarding the first point, new research that has shown that HIV-positive individuals who are on effective treatment are much less likely to transmit the virus to

30 Id.
31 Id.
others.\textsuperscript{32} It is therefore conceivably within the State’s public health interest to require notification of past partners, so that potentially infected individuals can be notified, receive testing, and be placed on treatment.\textsuperscript{33} This shift shows that the government’s interest in notifying partners might be stronger now than at the beginning of the epidemic. In the late 1980’s (or even in 1998, when the ACLU opinion peace was published) a positive test could allow an individual to refrain behavior that would pass on the disease to others. Now, however, the ability of treatment to reduce infectiousness of HIV means that with every individual who is tested and who subsequently receives and complies with treatment, there is less of a chance that that individual will pass on the disease regardless of his or her behavior.

The second point regarding the long incubation period remains scientifically true, but does not necessarily respond accurately to the policy goal of notifying those who are potentially infected. While it is true that a long incubation period could prevent determination of the cause of the infection, and may prevent notification of all potentially exposed partners, it is likely that some infected partners will be notified with the index patient’s permission.

Two key reasons for notifying partners of HIV-positive individuals are to “(1) provide appropriate services, including counseling, testing, and treatment, to those infected with the virus and (2) provide testing and prevention counseling to HIV-negative

\begin{flushright}
\textsuperscript{33} The problem remains, however, that many HIV-positive individuals cannot afford or access treatment.
\end{flushright}
individuals who have been exposed to HIV, in an effort to reduce risky behavior."\textsuperscript{34}

According to the CDC, identifying HIV-infected persons promptly after infection and directing them to medical care and prevention services is a national priority.\textsuperscript{35} This is because approximately 25\% of individuals living with HIV in the United States are not aware of their infection and are thus unaware of their own ability to transmit the virus to others. The CDC conducted a North Carolina-based study that determined that 20.5\% of sexual partners contacted and tested through partner notification services (PNS) had HIV infections that had not previously been diagnosed.\textsuperscript{36} In another study, 22\% of individuals contacted through PNS were newly identified as HIV-infected. “Overall, [the study] needed to interview 11 index patients to detect a new infection among partners.”\textsuperscript{37}

The second goal of PNS, to “provide testing and prevention counseling to HIV-negative individuals who have been exposed to HIV, in an effort to reduce risky behavior,” has less evidence to support its efficacy. A review of studies that were undertaken between 1985 and 1997 showed no indication that individuals contacted through PNS who were ultimately HIV-negative changed their behaviors as a result: “HIV-positive participants and HIV-serodiscordant couples reduced unprotected intercourse and increased condom use more than HIV-negative and untested participants.


\textsuperscript{36} Id.

HIV-negative participants did not modify their behavior more than untested participants.”

This review ultimately concluded that counseling and testing was not an effective prevention strategy for uninfected participants, despite the fact that the counseling received was as a result of their having potentially been exposed to the virus.\textsuperscript{38}

The CDC published recommendations for State Partner Notification Programs in 2008: “The following principles serve as the foundation for providing partner services to persons with HIV infection or other STDs and their partners:

\begin{itemize}
  \item \textbf{Client centered.} All steps of the partner services process should be tailored to the behaviors, circumstances, and specific needs of each client.
  \item \textbf{Confidential.} Confidentiality should be maintained and is essential to the success of partner services… When notifying partners of exposure, the identity of the index patient must never be revealed, and no information about partners should be conveyed back to the index patient.
  \item \textbf{Voluntary and noncoercive.} Participating in partner services should be voluntary for both infected persons and their partners; they should not be coerced into participation.
  \item \textbf{Free.} Partner services should be free of charge for infected persons and their partners.
  \item \textbf{Evidence based.} Partner services should be as evidence based as possible.
  \item \textbf{Culturally, linguistically, and developmentally appropriate.}
  \item \textbf{Accessible and available to all.} Partner services should be accessible and available to all infected persons regardless of where they are tested or receive a diagnosis and whether they are tested confidentially or anonymously…
  \item \textbf{Comprehensive and integrative.} Partner services should be part of an array of services that are integrated to the greatest extent possible for persons with HIV infection or other STDs and their partners.”\textsuperscript{39}
\end{itemize}


North Carolina’s Partner Notification Services, as defined by the control measures only meet some of these criteria. The law requires the NC PNS scheme to be confidential. It is free, and it is accessible and available to all. Under the studies cited above, the overall partner notification mechanism has been found to be effective, meaning that it is evidence-based. However, because North Carolina legally requires a newly infected individual to participate in partner notification, the PNS is not voluntary, noncoercive or client-centered. And, finally, due to the fact that treatment is not necessarily available to all who test positive in North Carolina, it is not “comprehensive and integrative.”

The DIS described at length the practical application of the partner notification interview. He emphasized that he felt that this was the most important part of his job, which seemed to reflect the knowledge that this method of contract tracing has proven results of diagnosing and bringing into care individuals who previously were unaware of their status. He stated that contract tracing is the “meat and potatoes” of disease intervention. He also stated that, when it comes to balancing emphasizing condom use and disclosure and trying to build a rapport that will engender trust and result in the reporting of partner names, “I don’t like to preach to people, I don’t like to be square. That’s one of the first things you learn. That can really turn people off and keep you from getting partners.”

40 The newly infected individual does have the choice between notifying his or her past partners personally and providing the DIS with partner names.
41 Discussed further in the ADAP and Treatment Availability section, below.
42 Eight of the Twenty-Six states with partner notification statutes have AIDS Drug Assistance Program (ADAP) waiting lists, meaning that low income, HIV-positive individuals in those states are being denied state funded treatment, despite being forced to comply with partner notification statutes. States with ADAP waiting lists: Statehealthfacts.org, “AIDS Drug Assistance Programs (ADAPs) with Waiting Lists or Other Cost-Containment Strategies, as of November 2011,” November, 2011, http://www.statehealthfacts.org/comparemapdetail.jsp?ind=552&cat=11&sub=204&yr=1&typ=5.
The DIS interviewee stated that “the CDC calls it partner services, and I kind of like to see it that way… I’m here to help them, and do all of it, some of it, or none of it, it’s their call.” He explains to them that assisting with the partner notification is their responsibility and that either they can notify their partners themselves, or he can do it for them in an anonymous manner. Again, he tries not to emphasize the legal requirement, but instead appeal to “what that person knows in their heart is right, [because] that’s when you might have a break through and get more names than you would have had you not said anything.” This particular DIS continues to utilize a conversational tone throughout his interview, but also tries to ensure that individuals who promise to notify their partners on their own really do so:

“I do try to assess whether they are really going to do it or not. If they say I’ll do it, I’ll take care of it, I try to see that it really gets done. At the very least, can you have them text me or email me, or just call me to let me know that they know what it’s going on. If they have a question about the infection I can address that for them, if they’d like me to save them a trip to the lab or the clinic, I can come draw their blood… save them a trip, maybe they’re the type of person who’s always meant to go down but they’re busy, but I can meet them after five, or sometimes on Saturdays or Sundays.”

The DIS also noted that a minimum of two interviews occur between him and each client, one in person and one follow up meeting either in the person again or over the phone. Some clients will reveal more names when he speaks with them the second time because a relationship of trust has been established.

Newly diagnosed individuals seem to be, according to the interviewees, most concerned with the confidentiality issue.

Physician: “I try to provide them with some background on the rationale for that, and explain to them that this partner notification is done
anonymously, so the people that he or she lists are not going to receive the patient’s name during the process... Many patients will then say to me, oh gosh, they’re going to know immediately, and you know, I might try to counsel them that, indeed, they might know immediately, they might not. It’s a very difficult circumstance, but in the interest of that individual’s health, with whom they had a relationship, notification and offering testing is a kind of responsible thing to do. And I try to say all of that in the context of a humane spirit, without judgment or any kind of condescension.”

Again, this is a situation where the interviewees have found it best not to focus on the legal ramifications surrounding partner notification, but instead on the rationale behind it and the idea that the client could be assisting someone else through notifying them.

Physician: “I’ve found the most successful way to do that is to constructively engage the person with HIV infection in real counseling, in saying to them that in the context of their relationship, we have an opportunity to really protect the health of the partner.”

The State Medical Director echoed the DIS’ sentiment that partner notification is the most useful and effective piece of the control measures. While he expressed his wish that the rest of the control measures be altered to be recommendations rather than legal requirements, he would retain the compulsory partner notification system:

“The goal here is for the DIS to bring people into care, identify those folks, counsel them, help notify partners, I think partners need to be notified still, and should be, I think that it’s actually very useful, we have very good data to show high yield on dealing with social networks. But they do that in a confidential manner, so no names are used, and the DIS in this case serve a purpose.”

There does seem to be a high level of trust in the patient to tell partners him/herself if s/he claims s/he will do so, despite the fact that there is evidence from a
trial in North Carolina that “leaving the notification of partners up to the subjects (patient referral) was quite ineffective.”

Medical Director: “So the person can decide that they’re going to notify their partners on their own, end of story. So when they’re interviewed with the DIS, they can say well I am notifying all my partners and I’ve done that thank you very much, that’s it.”

Physician: “Especially if they’re married, because I think that that is a technicality of the law… I want to make sure that their spouse is aware of their HIV diagnosis, and you say anyone that you’ve had sex with recently, are they aware that you’re HIV-infected?”

Interviewer: “How do you kind of ensure that a spouse is notified?”

Physician: “That’s a good question. It’s their word.”

That being said, one HIV-positive individual who went through the process felt less than trusted. One of the interviewees is himself HIV-positive, and was originally tested in North Carolina when anonymous testing was still available and subsequently moved to Chicago. Upon his return to North Carolina, he had to go to the hospital for a health issue. The hospital ran a viral load test, which was then reported to the state. Despite the fact that this individual had been positive for over a decade, he was still interviewed by DIS. While he seemed good spirited (and almost amused) about the fact that the interview had to take place at all, he got upset when the DIS insisted that she had to speak to his partner despite his insistence that the partner was aware of his HIV status. The individual pushed back, forbidding the DIS to visit his partner at his job (where he worked evening shifts) or to call during the day (when he was sleeping). The DIS would

not accept a phone call from the partner, maintaining that she had to be the one to call him. Ultimately, they decided on a time when the DIS would call the partner.

The individual interviewed for this study recognized that the extent to which he was able to push back against the system was a result of his position in the community. Subsequent to his experience with this “crappy system,” he became involved in revamping the DIS training program and also participated in training the DIS. He emphasized that, if the health department is going to do partner notification, they have to “meet the patient where they are, don’t come in as big brother, because then you’re going to get that wall up.” From the information gained from the DIS interviewed for this study, it seems that things have indeed changed:

DIS: “It’s changed over the years. Maybe it’s just me, but I kind of had the impression that when I first started, we were by any means necessary trying to get the partner information, almost like tricking people into doing it. I don’t think I was trained that way but maybe that’s what I took away from it… So I don’t put as much pressure to come out of that interview with names as I used to. I have a much more mature, logical way to look at it, if I take that approach with my clients things seems to work out.”

4.7 Disclosure of HIV-positive status to future partners

The policy motivations for mandatory disclosure of HIV status to sexual partners are relatively straightforward: if an individual is required to disclose his/her HIV status prior to engaging in a potentially risky activity, this allows his/her partner to make an informed decision about the proposed act in light of the risk of transmission. As a result of this informed decision, policy makers hope that the partner will either insist on practicing safer sex, or decline to engage in acts that could result in transmission of the disease at all, thereby reducing HIV incidence.
Studies have found that disclosure has “significant links to reduction in transmission acts, adherence to health regimens, and its relationship to mental health symptoms”\textsuperscript{45} but nevertheless, “a considerable percentage of seropositive persons (ranging from] 10\% to 60\% depending on the specific sex acts) continue to engage in unprotected sexual behaviors that place others at risk for infection…”\textsuperscript{46} On the other side of this coin, failing to disclose was not associated with an increase in risky sexual behavior, “indeed, as shown in a recent study, the prevalence of safer sex among non-disclosers was very similar to the prevalence of safer sex among disclosure… moreover, disclosure does not assure that safer sex will prevail, because some partners may engage in risky sexual activity even after being informed of their risk”\textsuperscript{47} On this note, the policy expert interviewed here noted that “disclosure is more difficult than condom use” because of the issues of stigma and rejection.

While it would certainly be ideal if HIV-positive individuals disclosed their status to every partner, it would also be ideal if all individuals generally took responsibility for their own health and discussed STDS (particularly HIV) with their prospective sexual partners. To place the burden of ensuring responsible, safe sex entirely on an individual exclusively because he is HIV-positive seems contrary to public policy. Through the control measures, North Carolina presumably hoped to relieve the fear of its citizens

\footnotesize
\textsuperscript{47} Id.
surrounding HIV, a fear that was particularly high during the beginning of the epidemic. However, by placing the burden entirely on the HIV-infected individual, and by leaving it there for over thirty years, the government allows the rest of its citizens to be complacent when it comes to safer sex and taking responsibility for their own health.

A study that examined the attitudes of US MSM regarding whether or not it should be illegal for HIV-positive individuals to have unprotected sex without disclosure resulted in an affirmative response by 64% of respondents. Even when broken down by age, political persuasion, and other categories, 55% or more of the respondents said it should be illegal.\textsuperscript{48} This same study noted that MSM who have not been tested may rely on their partner to disclose to them (and assume that they are negative if they do not say anything). This type of behavior “gains credibility” under laws like the North Carolina control measures. Ultimately, “placing legal responsibility exclusively on people living with HIV for preventing the transmission of the virus undermines the public health message that everyone should practice safe behaviors, regardless of their HIV status, and that sexual health should be a shared responsibility between sexual partners”\textsuperscript{49}

Multiple interviewees expressed concern about this uneven burden sharing:

STD Medical Director: “The other end of it is, we’ve gotten plenty of messages out to those that are negative that you can’t have sex with someone without taking responsibility for yourself. [But] the control measures basically say that well, you are responsible for what happens to


me, as opposed to I am responsible for what happens to me when it comes down to volitional sex.”

DIS: “…the law of the real world is if you don’t protect yourself, the real world will give you whatever comes to you. I mean, you open yourself up to anything, I guess might be a more compassionate way to say that.”

Policy Expert: “In 2012 it is not a situation where one person “gave it” to another, positive is negative and negative is positive, at this point it should be everyone’s responsibility.”

Despite the fact that policy experts would hope this responsibility would be shared by all individuals who are engaging in sexual relationships, regardless of status, two of the interviewees expressed concerns that certain populations, particularly young MSM, are not taking the proper steps to protect their own health.

Executive Director: “I’ve got a fourth generation coming along, and it’s just horrible. Young gay men, I tell you… they don’t take care of themselves, and that’s what frightens me, because if [a requirement to disclose] isn’t in place, and the obligation isn’t there, there’s a generation who doesn’t value themselves well enough [to protect themselves], and that frightens me.”

While the Executive Director also recognized that the law probably cannot help instill self-worth in these young men, thereby empowering them to protect their own health. However, he is so fearful for their future that he would rather have the disclosure laws in place, so at least some individuals are required to initiate conversations about status prior to sex. One physician interviewed expressed a similar sentiment:

Physician: “[Recently, at the clinic in Fayetteville,] I saw two new cases of syphilis in two young black men, both 22, one had been in college and one was working, but they both had had syphilis after learning that they had HIV. And I just thought, this population of pretty bright, engaging, people, not derelicts, they still don’t get it. And having a STI like syphilis and [also having] HIV amplifies the risk of transmission, so I still don’t think the legal system is the way to [increase awareness], but somehow… [These young men] weren’t alive and they don’t see people who look horrible with HIV and AIDS, Tom Hanks in Philadelphia, that just isn’t
around anymore, there’s been a revision of behaviors kind of back towards that generally unhealthy behavior strategy”

On the other hand, the DIS did note that some clients recognize their own responsibility in becoming infected with the disease. When participating in partner notification, they emphasize they are not interested in any type of prosecution (or causing any named individual to be considered a control measures violator, which, as outlined above, is not necessarily within their control), and essentially indicate that “I knew what I was getting into, I knew the risks, I’ll take ownership and responsibility for that.”

4.8 Mandatory Condom Use

As was mentioned above, even individuals who intend to exclusively have sex with condoms do not end up doing so. Overall, the studies done on the subject have indicated that HIV-infected people do not utilize condoms consistently, or for all acts that can potentially transmit the disease. One study found that, with respect to anal sex, whether or not an individual’s State had a specific law on the topic had no significant association with increased condom use. Recognizing that he will not be able to be “wherever they’re having sex at… for the rest of their lives,” the DIS introduces the idea of using condoms to his clients as follows:


“Here’s the law, here’s what North Carolina expects of people, this is the law, these were put into place to protect you as well as the public. So as far as condom use, we offer the free condoms, they know they can get them for free at the health department.”

In addition to there being no indication that a prohibition on unprotected sex does anything to change behavior, on the face of the control measures there is no provision for opting out of condom use. This is clear from the language of the regulations themselves: “Infected persons shall refrain from sexual intercourse unless condoms are used…”

While the regulations in various other states include language that relaxes or waives the condom requirement subsequent to disclosure and informed consent on the part of the partner, North Carolina’s requirements have no such language. Surprise was expressed by almost all of the interviewers that this was the case. The surprise reflected both discomfort with this level of government oversight in private affairs and also the fact that this is not the way in which the law is enforced.

AIDS Organization Director: “If [both individuals] are informed with external sources [about their serostatus and viral loads]… they are now capable of deciding what they are comfortable with. [The fact that an individual cannot consent out of condom use] is absurd”

Physician: “That’s a bit too much Big Brother…”

County Health Director: “[Even] if that is what the law says, that is not what happens in the real world.”

Medical Director: “But if [a positive individual is] having sex with someone else who’s known to be HIV-infected, you know what, I don’t think the state should be involved in that. If they disclose to someone that they’re HIV-infected and that person decides to have unprotected sex [regardless], guess what, the state shouldn’t be involved with that.”

Despite the expression of these sentiments, it seems that, practically, the most common “trigger” for a control measure breach does, to some extent, require that the
condom use requirement and the disclosure requirement to both be considered binding. If it is indeed acceptable for someone to “opt out” of condom use through obtaining their partner’s informed consent, then an incident STD infection does not necessarily indicate a breach of control measures. The County Health Director elaborated on the way in which this inconsistency is dealt with in practice: “If I as a health director were faced with a situation where somebody, let’s say an HIV+ individual was partnered with an HIV- individual and the HIV- individual was fully aware of his or her partner’s status, that I would not become involved in control measure violations.” Therefore, if an HIV-infected person who is accused of breaking control measures can produce a partner who was also infected with the other STD that raised an incident infection flag, who will state that he or she was informed of the HIV status and consented to unprotected sex, criminal charges (or a lesser isolation order) would not be issued against the index patient under the jurisdiction of the County Health Director interviewed.

The AIDS Organization Director also voiced concern over “he said, she said” situations in light of the dual condom use/disclosure requirement: “What if you get a jilted lover whose opt out is irrelevant [because he or she denies that it], that’s a big problem…” This concern is could also be applied to the disclosure requirement – an individual could claim that disclosure did not occur, despite the fact that it did. That having been said, it was echoed by multiple interviewees that without consistent documentation of breaches, typically including evidence of an incident infection, charges will not be raised under the control measures. Therefore, statements made by one jilted
lover would likely not be sufficient to result in criminal sanctions being brought against an HIV-positive individual.

The fact that there is such a large discrepancy between what the control measures say and how they are enforced is concerning. The County Health Director’s explanation reflects the ways in which consensual adult relationships occur, but the control measures do not. It is fortunate that the actual implementation of the laws takes a more reasonable stance on this issue, but it seems simply unfair for the individuals regulated by these rules that what is actually prohibited is so unclear.

### 4.9 Do the Control Measures Impede Care?

One theme that arose in all of the physician interviews, and also in the interviews with the DIS and the State Medical Director, was the idea that giving the best care to a patient may be at odds with enforcing the control measures to their fullest extent. This is particularly significant in light of the general emphasis on both getting individuals into care and keeping them there. The DIS indicated that this is something that he’s quite sensitive to during the course of his interactions with the client:

DIS: “I’m not making them do anything they don’t want to do, I’m not having them reveal information that they might regret later, because whether they, whether it’s logical or justified or not, they kind of see you as the face of HIV and the control measures. I try to leave a good taste in people’s mouth so they get into care and they stay in care.”

One of the physicians noted, too, that an individual’s first appointment is not the best time to start emphasizing their newly acquired legal responsibilities, in addition to discussing their newly acquired disease.

Physician: “I don’t think it benefits them or changes their behavior to try to couch it in terms of the legal ramifications of their circumstances.”
They’re struggling to come to grips with their new knowledge and I talk to them at some length about the disease…”

Physician: “Because HIV is such a stigmatizing illness, and there’s a lot of anxiety especially around an initial visit, I don’t want to kind of put on my police hat in an initial encounter, and convey to them that that’s a major concern of mine, when my job as a physician is to care for the patient in front of me.”

There was a high level of awareness that enforcing the control measures, at least on the part of the physician, could result in the ruination of the physician/patient relationship.

Physician: “I think that if I threw the bus on them and I break that relationship with my patient, I’m not sure I’d actually be doing society a great favor, because they would probably fall out of care.”

The idea that the patient could potentially fall out of care, when linked with the new data from the 052 study regarding transmission risk for individuals with no viral load, has significant ramifications, as expressed by one of the physicians:

“I don’t want to put the public at risk, but I also think that I’m probably going to do more good if I maintain a relationship with my patient and kind of advise them. And maybe that’s making compromises, maybe that means that I told them to use condoms but they’re not using condoms. But again, if I just kind of turn them over to the health department, they’re going to… they will drop out of care, and then their viral load may go up, and that’s what’s going to really put the public at risk, I think that’s what 052 has demonstrated to us.”

This issue is particularly significant when one considers the idea of incident STD infections. As has already been discussed, if an HIV-positive individual tests positive for syphilis, this can be used as evidence that they have broken control measures. Physicians

are aware of this and some patients are too. Some physicians indicated that they feel that, if they were to test for these incident STDs, particularly asymptomatic ones, and the patient does come back positive, and does receive inquiries from the health department, that the patient will then feel that s/he has been betrayed by that doctor. This concern results from the State and Local Health Director’s legal authority to request copies of any medical records under N.C.G.S. 130A-144(b). The State Medical Director expressed this concern as well:

“Same thing with physicians, [we’re putting them in a bad position], what we’re pushing for on a national level is to be doing STD screening for asymptomatic infections in HIV-infected folks in care… [but] what we’re seeing is physicians either not asking or not putting in the medical record because they’re worried about what might happen with that information at some point.”

The medical director also emphasized that these asymptomatic infections can increase the risk of transmission. Therefore, if the control measures are preventing or dissuading physicians screening for such co-infections, this could very potentially be having a negative effect on public health.

Along these same lines, all the physicians interviewed raised the idea that they were assisting their clients to manage their (and other’s) risks. Risk management is also somewhat at odds with strict enforcement of the control measures, but in the physician’s opinions is more reflective of both the impulsive nature of sexual behavior, and our most recent knowledge regarding the disease.

“And so I’ll often tell patients that there’s nothing in life that doesn’t have some risk associated with it… Life is full of risks. And if you want to avoid being seriously injured through a motor vehicle accident, you could never get in a car again, you could drive safely or take a defensive driving course, you could wear a seatbelt. And the risk kind of goes from 0 to
some other low number, and the same is true for HIV transmission risk. If you want the risk to be zero, don’t have sex. If you want it to be close to zero but not necessarily zero, use condoms, and if you want a risk that’s even higher but still relatively low, you can have [unprotected] sex, although my recommendation is that you use condoms, but it’s your choice, if you’re on antiretroviral therapy, and your viral load is suppressed, the risk is pretty low, so just trying to [help the patient] understand the risk and make a decision.”

This sentiment means that, if someone comes in with an incident STD, the first question is really “what’s their viral load?” If their viral load is undetectable, and has been for some time, while the physician may still be “unhappy,” he can still feel that he’s done everything else possible to minimize the risk to the uninfected population.

4.10 Physician Perceptions of Disease Intervention Specialists

Overall, the physician interviewees spoke very highly of the Disease Intervention Specialists. The physicians indicated that they typically tell their patients what to expect from the DIS visit, not to warn them, but to make it a more productive interaction for all involved.

Physician: “I inform them that one of the ways in which we have tried to control the epidemic is a time honored approach to managing STIs called contact tracing, and that to that end, we want to know if we can from whom they became infected, and also if they have infected anyone else, we would like those people to become aware of it, so that they can come into care for their own benefit and also to prevent additional transmissions, and in order to accomplish that, the state has a program where someone will come out and interview them… in order to try to maximize the valuable information that they share with the DIS group, I try to reassure them that there is no by-name notification, that it’s just all intended to help control the epidemic, and whether they hear it that way or not I don’t know, but I do tell them.”

The Physicians interviewed seemed to think that this kind of preparation was productive, noting that if they did let their patients know to expect the DIS
communication, the patient tended not to be upset by the interaction. In the few cases
where the physician was not able to inform the patient, it was more likely that the newly
diagnosed individual would have concerns about the meeting with the DIS:

Physician: “But for whatever reason they didn’t hear it from me… then
sometimes they come and they’re really unhappy about it because they
have this sense that someone has a list of all the names and now they’re on
the list, and their confidentiality is in jeopardy and so on…”

One interesting part about how the contract tracing occurs in North Carolina, that
was briefly mentioned when describing the Executive Director’s experience with the DIS
above, is that if someone who has been living with HIV for years moves into the state,
they are still required to go through this process: if they seek treatment in North Carolina,
their HIV-positive status is reported to the state, and a DIS will subsequently contact
them to set up an interview. Two of the physicians interviewed shared anecdotes about an
individual in this type of situation being quite upset by the DIS visit. This may be
because the physician failed to inform these patients to expect a visit from the DIS due to
the fact that they were not newly diagnosed. The DIS interview could also seem like a
more significant intrusion into the life of someone who has already been living with and
dealing with the disease for an extended period of time, particularly if the state they had
previously been living in had less stringent rules. Overall, however, patients reported to
the physicians that the DIS were sensitive, both towards the individual and in regards to
their confidentiality.

The State Medical Director, who is in a supervisory role for the DIS, stated that
he, in his role as a physician, does not tell his patients to expect a visit from the DIS: “I
think that that puts DIS into a really strange position, because the DIS only do what the
law requires.” This is an interesting discrepancy, particularly due to the fact that of all the interviewees he is probably the most familiar with the nuances of the DIS work.

4.11 The HIV Prevention Trial Network’s 052 Study – treatment as prevention

One theme that arose in the majority of the interviews was the results from 052, a randomized clinical trial that “demonstrated that antiretroviral therapy reduces the sexual transmission of HIV in HIV-serodiscordant couples by more than 96%”. This is very exciting news for the HIV/AIDS Community, and was lauded by Science Magazine as the Scientific Breakthrough of the Year. The news that successful treatment is associated with a much lower risk of transmission, while positive information overall, also complicates various aspects of the control measure implementation. Most physicians did tell their patients about the study, primarily to encourage them to adhere rigidly to their antiretroviral regimens.

Physician: “There is obviously recent information now that shows that successful treatment is associated with a much lower risk of transmission, I use that to incentivize them taking their medicine correctly.”

However, there are some limitations to the extrapolation of this study to the populations, and individuals, that physicians are dealing with – something that the physicians also try to communicate to their patients:

Physician: “I am at pains to tell them that for an individual that the information we have is for a population of people [and that] for any one individual it is possible to transmit virus even if you’re on successful therapy.”

Physician: “[The study was done in a] heterosexual population, and frequently when I’m having this conversation my patients are gay, and so that’s a different population, and I say I can’t necessarily extrapolate 96% reduction in a heterosexual, primarily African population to 96% reduction in a homosexual population in Durham, I don’t know what that number is, but it probably approximates it to some degree. So anyways, I think that that actually has to be a part of the conversation as well, and I know that that’s not in the control measures.”

Overall, 052 is heartening news for the HIV/AIDS Community. In addition to demonstrating the breadth of ARV effectiveness, it may also incentivize policy makers to make more money available for earlier treatment, as this could potentially decrease the incidence of HIV overall. However, this new information also interacts in a problematic way with the control measures. In light of 052, the requirements that HIV-positive individuals utilize condoms and disclose their status to their partners are undermined. If the purpose of these restrictions is to decrease HIV incidence, then it seems that an individual with a zero detectable viral load who is adhering to his or her medication should perhaps be exempt from these requirements. Even if this is not a position that would be supported among the general community, multiple physician interviewees did indicate that this is how their patients view this news.

4.12 The ways in which the Internet has altered partner notification services

Another major way that the world has changed since the control measures were implemented was the invention of the Internet and its subsequent spread to almost every aspect of life. Some interviewees noted that the Internet increases the average HIV-
positive individual’s access to information about the disease. This information includes both updates on HIV medical care, such as the results of 052 and news on the control measures specifically. It is not challenging to find specific incidents of the control measures being enforced, one only needs to Google “North Carolina control measures.” While examples can be found, however, it is clear from the results that people are punished under these regulations very rarely. This is the type of information that might have been more difficult for an individual to acquire 15 or 20 years ago.

A more significant Internet related theme, however, was the way it is utilized to facilitate sexual encounters, particularly in the MSM community. The Internet increases the availability of casual sex, which is often also anonymous. These trends in sexual relations, and the increase in risk factors associated with more casual encounters, are something that the physician interviewees are certainly aware of:

State Medical Director: “The other thing that’s happening at the same time, right now is that we have a lots of anonymous sex, people are meeting over the internet. They don’t know the other person’s name and the other person doesn’t know their name. They don’t want to be found and they don’t want the other person to find them. So there’s no disclosure, and as a result we don’t know anything about the other person’s status, and they don’t ask. Cause they don’t want to know and again, the control measures [do] nothing to help with that.”

Physician: “I was at one of these meetings in Atlanta, and the guy sitting next to me was a speaker, and I was sitting there, and I didn’t mean to, but I looked, and he had all this like porn stuff on his computer screen right next to me... Then he turned out to be the next speaker, and he got up and he said I think I just really freaked out the guy next to me, but he said ‘in the time that I was sitting there, I got on some chat room or something for gay men in Atlanta, and I had six offers for someone to have sex with me anonymously, like just in the last half hour.’”
These sexual patterns raise interesting issues surrounding disclosure, and also present challenges to the DIS who are trying to carry out the State partner notification scheme.

Regarding disclosure, one study indicated that individuals have an expectation that any statement regarding HIV status in an online profile will be accurate, with 85% of study respondents relying on this information while making sexual decisions. However, the study also indicated that many of these individuals also talk in person about their partner’s HIV status prior to a sexual encounter, as well.

The interviewee who is HIV-positive provided an example of the problems that this can raise. He explained that he started to use Grindr to seek out casual relationships. Grindr is an application that can be downloaded onto a smartphone or tablet and is utilized by MSM to set up both casual sexual encounters and, sometimes, dates. Each individual has a single picture as their icon and these icons are displayed as a grid. When one clicks on a picture, a written profile is pulled up.

The individual created a “test” profile, in order to try out the free version of the application without being too public with his identity. Ultimately, he purchased the application and created a full profile. He identified himself as HIV-positive and explained what he did for a living. He saw this as an opportunity to both “meet people and also educate.” He noted, “there are not a lot of people on Grindr who say they’re HIV-positive, it’s not a real hook up line.” He proceeded to have sex with individuals he met through the application who were all HIV-positive “as far as he knew,” and they

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disclosed either online and in person. Things were complicated, however, by an individual he had a sexual encounter with who had contacted him through the original “test” profile. Once the interviewee realized that the mistake had been made, he realized he hadn’t actually disclosed to this partner, because his test profile did not state his HIV-positive status. The individual immediately informed the partner and insisted he get tested.

This story demonstrates the ways in which interactions that begin online can complicate the implementation of the control measures. This interviewee expressed that he is typically very careful about disclosure and he felt that listing his HIV-positive status on his profile was sufficient notice to the other person. Even without the complication outlined above, it is interesting to consider the ways in which disclosure can be made. The control measures do not define the manner in which HIV status must be disclosed, and the Internet certainly creates a myriad of alternative ways in which someone could do so.

These sexual practices also greatly complicate the efforts of the DIS who are attempting to complete partner notification.

State Medical Director: “They don’t know who they’re having sex with, they don’t know how we can find them, they don’t know anything about them except their handle online from some site…”

However, multiple studies have shown that MSM are very open to the idea of receiving partner notification via the Internet, regardless of whether or not their initial interaction with their sexual partner was online. In one study, 81% of participants (all MSM) “reported that it would be important to them to receive a partner notification email if they
had been exposed to a sexually transmitted infection.”\(^57\) Additionally, there was willingness on the part of the study participants to initiate notification online as well. Another study, in the MSM community in San Francisco, found that many individuals told their primary partners when they had been diagnosed with an STD, but did not notify their casual sex partners. However, these same respondents “overwhelmingly said that if there was an easy, convenient, and anonymous way to inform their partners of their potential disease exposure, they would use it.”\(^58\)

It seems, therefore, that if North Carolina were to contact potentially exposed individuals through the same lines of communications as HIV-positive individuals are using to communicate with potential sexual partners, the general response to such notifications would be positive. North Carolina started allowing email notifications in 2006, according to the DIS interviewed. The email sent is “almost like the letter on the doorstep,” and requests that the individual contact the DIS about a confidential health matter. The State also provides notification through sites and apps like Adam4Adam.com, BCGLive.com, Manhunt, and Grindr. This type of notification started in 2009 and the DIS interviewed has been in charge of this effort since 2011.

DIS: “We said hey, any site that has to have a profile, we’ll set up a profile and notify [the exposed individual] or have them call us. So we did facebook, myspace, anything.”


Basically the DIS will now take any information that a newly diagnosed individual will give them, including emails, nicknames, or usernames and utilize these to attempt to notify as many partners as possible.

DIS: “Usually the usernames are so unique that if one letter or something is off, you’re not going to be able to find it on the site. Sometimes you can narrow it down to one or two, but you’re not sure, and you don’t send those people [notifications]… [but you can] ask your index or your original patient, ‘this is what I come up with, which one is it?’ And then proceed from there.”

This new approach clearly expands the number of individuals who may potentially be notified, and subsequently tested.

The DIS also explained that some of these websites have a mechanism for “legitimizing” health department employee profiles. Adam4Adam, for example, “will give [the DIS] a stamp of approval, so the patient or client can contact the liaison at the website to see if it’s legit or not.” Manhunt has a similar mechanism, and North Carolina had been using this type of special profile on that site, but there were complaints about a breach of confidentiality:

DIS: “two people complained that their confidentiality was breached through us doing that, and from what I know about the actual investigations, it was someone who was a previous positive who was angry that it could result in prosecution, because of [a] syphilis [diagnosis].”

It is unclear, exactly, what “confidentiality” the individuals believed had been breached, but it seems as if they complained to the website, who responded by revoking North Carolina’s “special” health profile. In response, the DIS contacted the Senior Health Strategist at Manhunt. They had a conference call, and tried to determine what it would take for North Carolina to have such a profile again. The Manhunt representative
had two requirements: (1) that the letter explicitly state if the exposure was for HIV (instead of being more vague) and (2) the State had to promise that it would not use the information they obtained through this profile to prosecute anyone. The State Health Department was not comfortable with the first requirement. While the DIS are currently allowed to explicitly mention syphilis exposure, they are not allowed to do so with HIV. The second requirement could obviously not be met, due to the control measures.

4.13 ADAP and Treatment Availability

Finally, multiple interviewees brought up the cost and limited availability of treatment. The Executive Director brought up the contradictory messages that the State puts forward: they want to maximize the amount of people being tested and brought into care, but according to their ADAP waiting list (the seventh longest in the country), they do not have the resources to provide newly diagnosed individuals with treatment if they cannot afford it themselves. The Executive Director emphasized the fact that, while HIV is not a death sentence for some individuals, it remains so for others.

Executive Director: “Getting HIV for [certain people] could be a death sentence, or their family could abandon them, or the stigma would be so great that they would commit suicide, or they don’t have health insurance, the list goes on and on… To say it’s not a death sentence isn’t true, it’s a death sentence if you don’t have [certain elements of support], if you just change the words around: It isn’t a death sentence if you have, and it is a death sentence if you don’t have. And that makes it a public health crisis, which means that public health measures are appropriate and should be there.”

The State Medical Director has a more positive outlook, although he recognized the limitations on the care available.

State Medical Director: “Even though we have a waiting list virtually everyone in the state who requires meds will get them. We have compassionate programs through the pharmaceutical companies…, there are clinical studies for many of these folks, I am not aware of many folks, if any, that are supposed to be on Anti Retroviral Therapy but can’t get it through some mechanism. The problem is that it’s piecemeal, and there may be a delay in doing that, and that’s not good…”

He also noted that approximately 80% of the State’s HIV-positive individuals will be eligible for Medicaid under Health Care Reform.

Despite the fact that the State Medical Director emphasizes that everyone who needs ARVs can get them in some way, there is a public perception that there is a waiting list, and that even if someone is diagnosed as positive, he or she may not be able to receive treatment.

State Medical Director: “So if I’m poor and I don’t have health insurance or if I’m Latino and I’m not a documented person in the country, I may believe that if I’m diagnosed, there’s only a downside for me. I’ll go broke, I’ll be removed from the country, I’ll be ostracized from my community, and there’s no treatment [available to me].”

It is a political problem: the State needs to be able to point to a waiting list in order to fight for increased funding from the Federal Government, but then individuals receive the message that there is not medication available, which makes getting tested seem fruitless.
5. Summary of Findings

First, the level of familiarity with the control measures varies greatly between individuals in different occupations. Even those in positions of legal power are not legally familiar with the text of the regulations. For example, the County Health Director was surprised that the control measures do not allow HIV positive individuals to opt out of condom use.

Secondly, the implementation of the control measures by DIS is relatively standardized, but the enforcement of the control measures is done county-by-county and there is little to no transparency on how this is done, and if it is applied equally across sexual orientations and races. There are also issues with the philosophy behind enforcement of the control measures: incarceration is not a good option for HIV positive individuals; normative behavior is likely better encouraged through more positive interventions; and, the control measures do not seem to be effective at deterring risky behaviors, despite the threat of punishment that exists. Overall, none of the interviewees believe that the control measures were particularly effective at fulfilling the public health goals for which they were implemented.

Third, partner notification is effective at bringing new people into care, but because of the criminal sanctions tied to the control measures, North Carolina’s current partner notification system is perhaps less effective than it might be. Multiple interviewees indicated that partner notification services are the only effective piece of the control measures.
Finally, the requirements of disclosure of status and condom use are not particularly effective at causing HIV positive individuals to follow through on this behavior. This is due both to the stigma surrounding the disease, and the irrationality of sexual decision making. Finally, the fact that an adult cannot opt out of condom use upon giving informed consent is concerning because of the limitations it places on adult autonomy.
6. Study Limitations and Strengths

The main limitation for this study was the very short time frame during which the research had to be completed. This limitation was exacerbated by the fact that it took over two months to obtain IRB approval, because of confusion as to which board needed to approve the project. Secondly, because of the limited time frame, there was also a limited availability of interviewees. Many individuals who were contacted regarding participation were interested but were not ultimately available during the time period that the interviews were conducted.

Additionally, the connections that the study had with potential interviewees was limited in geographic area. This resulted in all of the interviewees being located in only three of North Carolina’s one hundred counties. This could skew the results both because of the small area, and also because this specific area (Durham, Wake and Orange Counties) is thought of as having a different political outlook from much of the rest of the state. Additionally, approval was not gained for the inclusion of HIV-positive individuals in this study. Therefore, the perspectives outlined did not include the very individuals who are governed by the control measures.

A single interviewer conducted all of the interviews. The interviews certainly became stronger and more consistent over time, but this increase in quality added to the inconsistency of the interviews overall. The interview guides did not reflect the fact that, after the first few interviews, other themes had arisen from each of the interviews. The DIS interview guide was most on-target, due to the fact it had been piloted with a DIS
who was not subsequently interviewed. The other interview guides would have benefited from additional vetting and professional review, as well.

Study strengths included the length and depth of the interviews, and the fact that during many of them a wide variety of issues could be discussed. The open-ended nature of the interview guide allowed unexpected, but quite interesting, topics to arise. Additionally, the individuals who were interviewed are some of the most well respected individuals in the area’s HIV community, and many would be involved in any policy change that did occur, were the control measures to be altered. Finally, the fact that the interviewer has a legal background allowed for an accurate comparison of the statutory and regulatory schemes with the actual implementation of the control measures on the ground.
7. Recommendations for Future Work

This study, as described above, was limited in geographic scope. It was also limited by the fact that approval could not be obtained for the inclusion of HIV-positive individuals, who are actually governed by the control measures. Likely the most helpful expansion on this work would be a larger study that interviews HIV-positive individuals. Additionally, further interviews with each “type” of interviewee would add to the understanding of the control measures as a whole. Interviews with other DIS and other County Health Directors would be very helpful, as they would allow for a much more comprehensive understanding of how the control measures are implemented on the ground. Interviews with other DIS would also be beneficial, particularly if DIS who work in the more rural areas of the state were included.

Collection of data surrounding whether or not physicians are actually failing to test for asymptomatic STD infections because of the fact that such incident infections are utilized as evidence of control measure violations would also be beneficial. Finally, collection of data, by county, of how often and to what extent the control measures are enforced would be an enormously helpful project. This data could be used to determine whether or not enforcement is disparately applied across geographic areas, racial groups or various sexual identifications.
8. Conclusion

Due to the exploratory nature of this study, more questions were raised than answers obtained. However, it seems that a few trends can be summarized that may be useful in defining future research in this area.

First, the world, the HIV Community, and our scientific knowledge regarding HIV have changed drastically since the control measures were implemented. We are aware of how the disease is transmitted and there are multiple treatments available. These treatments also help prevent the spread of the disease. The Internet has changed the ways in which people communicate and they ways in which they initiate sexual relationships. All of these developments affect large scale changes in the way the disease is dealt with nationwide; all of these developments represent strong reasons that the control measures should be, at the very least, reconsidered to make sure they still make sense in light of the world as it is today. One physician summed it up as follows: “[These control measures] are the legacy of times past, and our imperfect knowledge, and a lot of fear, and trying to err on the side of caution in terms of not putting people at risk.”

Secondly, almost all of the interviewees, even those who generally support the existence of the control measures, admit that they do not believe that the control measures are changing behavior. While this is only a small-scale study, and this represents the perceptions of only eleven people, it is a cross section of those most involved with the epidemic and the affected community in North Carolina. If these regulations are not changing behavior, or if the change is negligible, then the regulations potentially will not withstand a balancing test against the negative effects they might be
causing. More information should be collected regarding the negative effects – for example, how many physicians are failing to test for asymptomatic infections in order to protect their clients from control measure inquiries – so that this balancing test can be fully informed.

Finally, the general lack of transparency regarding the way these regulations are implemented is concerning, particularly in light of interviewee concerns about the potential for unequal application of the law. At the very least, information regarding enforcement should be gathered on a statewide level, and this information should be made public, so that it is clear in what manner and against whom these measures are implemented. This information should not be limited to those individuals against whom a warrant is issued, but also expanded to include those who receive warnings from the health department and those who receive official isolation orders. This will ensure that HIV-positive individuals have the opportunity to fully understand the ways in which these regulations are implemented and enforced, so that they can act accordingly.
Appendix A

10A NCAC 41A .0202
CONTROL MEASURES – HIV

The following are the control measures for the Acquired Immune Deficiency Syndrome (AIDS) and Human Immunodeficiency Virus (HIV) infection:

1) Infected persons shall:
   (a) refrain from sexual intercourse unless condoms are used; exercise caution when using condoms due to possible condom failure;
   (b) not share needles or syringes, or any other drug-related equipment, paraphernalia, or works that may be contaminated with blood through previous use;
   (c) not donate or sell blood, plasma, platelets, other blood products, semen, ova, tissues, organs, or breast milk;
   (d) have a skin test for tuberculosis;
   (e) notify future sexual intercourse partners of the infection;
   (f) if the time of initial infection is known, notify persons who have been sexual intercourse and needle partners since the date of infection; and,
   (g) if the date of initial infection is unknown, notify persons who have been sexual intercourse and needle partners for the previous year.

2) The attending physician shall:
   (a) give the control measures in Item (1) of this Rule to infected patients, in accordance with 10A NCAC 41A .0210;
   (b) If the attending physician knows the identity of the spouse of an HIV-infected patient and has not, with the consent of the infected patient, notified and counseled the spouse, the physician shall list the spouse on a form provided by the Division of Public Health and shall mail the form to the Division. The Division shall undertake to counsel the spouse. The attending physician's responsibility to notify exposed and potentially exposed persons is satisfied by fulfilling the requirements of Sub-Items (2)(a) and (b) of this Rule;
   (c) advise infected persons concerning clean-up of blood and other body fluids;
   (d) advise infected persons concerning the risk of perinatal transmission and transmission by breastfeeding.

3) The attending physician of a child who is infected with HIV and who may pose a significant risk of transmission in the school or day care setting because of open, oozing wounds or because of behavioral abnormalities such as biting shall notify the local health director. The local health director shall consult with the attending physician and investigate the following circumstances:
   (a) If the child is in school or scheduled for admission and the local health director determines that there may be a significant risk of transmission,
the local health director shall consult with an interdisciplinary committee, which shall include school personnel, a medical expert, and the child's parent or guardian to assist in the investigation and determination of risk. The local health director shall notify the superintendent or private school director of the need to appoint such an interdisciplinary committee.

(i) If the superintendent or private school director establishes such a committee within three days of notification, the local health director shall consult with this committee.

(ii) If the superintendent or private school director does not establish such a committee within three days of notification, the local health director shall establish such a committee.

(b) If the child is in school or scheduled for admission and the local health director determines, after consultation with the committee, that a significant risk of transmission exists, the local health director shall:

(i) notify the parents;

(ii) notify the committee;

(iii) assist the committee in determining whether an adjustment can be made to the student's school program to eliminate significant risks of transmission;

(iv) determine if an alternative educational setting is necessary to protect the public health;

(v) instruct the superintendent or private school director concerning protective measures to be implemented in the alternative educational setting developed by school personnel; and

(vi) consult with the superintendent or private school director to determine which school personnel directly involved with the child need to be notified of the HIV infection in order to prevent transmission and ensure that these persons are instructed regarding the necessity for protecting confidentiality.

(c) If the child is in day care and the local health director determines that there is a significant risk of transmission, the local health director shall notify the parents that the child must be placed in an alternate child care setting that eliminates the significant risk of transmission.

(4) When health care workers or other persons have a needlestick or nonsexual non-intact skin or mucous membrane exposure to blood or body fluids that, if the source were infected with HIV, would pose a significant risk of HIV transmission, the following shall apply:

(a) When the source person is known:

(i) The attending physician or occupational health care provider responsible for the exposed person, if other than the attending physician of the person whose blood or body fluids is the source of the exposure, shall notify the attending physician of the source that an exposure has occurred. The attending physician of the
source person shall discuss the exposure with the source and, unless the source is already known to be infected, shall test the source for HIV infection without consent unless it reasonably appears that the test cannot be performed without endangering the safety of the source person or the person administering the test. If the source person cannot be tested, an existing specimen, if one exists, shall be tested. The attending physician of the exposed person shall be notified of the infection status of the source.

(ii) The attending physician of the exposed person shall inform the exposed person about the infection status of the source, offer testing for HIV infection as soon as possible after exposure and at reasonable intervals up to one year to determine whether transmission occurred, and, if the source person was HIV infected, give the exposed person the control measures listed in Sub-Items (1)(a) through (c) of this Rule. The attending physician of the exposed person shall instruct the exposed person regarding the necessity for protecting confidentiality.

(b) When the source person is unknown, the attending physician of the exposed persons shall inform the exposed person of the risk of transmission and offer testing for HIV infection as soon as possible after exposure and at reasonable intervals up to one year to determine whether transmission occurred.

(c) A health care facility may release the name of the attending physician of a source person upon request of the attending physician of an exposed person.

(5) The attending physician shall notify the local health director when the physician, in good faith, has reasonable cause to suspect a patient infected with HIV is not following or cannot follow control measures and is thereby causing a significant risk of transmission. Any other person may notify the local health director when the person, in good faith, has reasonable cause to suspect a person infected with HIV is not following control measures and is thereby causing a significant risk of transmission.

(6) When the local health director is notified pursuant to Item (5) of this Rule, of a person who is mentally ill or mentally retarded, the local health director shall confer with the attending mental health physician or mental health authority and the physician, if any, who notified the local health director to develop a plan to prevent transmission.

(7) The Division of Public Health shall notify the Director of Health Services of the North Carolina Department of Correction and the prison facility administrator when any person confined in a state prison is determined to be infected with HIV. If the prison facility administrator, in consultation with the Director of Health Services, determines that a confined HIV infected person is not following or cannot follow prescribed control measures, thereby presenting a
significant risk of HIV transmission, the administrator and the Director shall develop and implement jointly a plan to prevent transmission, including making recommendations to the unit housing classification committee.

(8) The local health director shall ensure that the health plan for local jails include education of jail staff and prisoners about HIV, how it is transmitted, and how to avoid acquiring or transmitting this infection.

(9) Local health departments shall provide counseling and testing for HIV infection at no charge to the patient. Third party payors may be billed for HIV counseling and testing when such services are provided and the patient provides written consent.

(10) HIV pre-test counseling is not required. Post-test counseling for persons infected with HIV is required, must be individualized, and shall include referrals for medical and psychosocial services and control measures.

(11) A local health department or the Department may release information regarding an infected person pursuant to G.S. 130A-143(3) only when the local health department or the Department has provided direct medical care to the infected person and refers the person to or consults with the health care provider to whom the information is released.

(12) Notwithstanding Rule .0201(d) of this Section, a local or state health director may require, as a part of an isolation order issued in accordance with G.S. 130A-145, compliance with a plan to assist the individual to comply with control measures. The plan shall be designed to meet the specific needs of the individual and may include one or more of the following available and appropriate services:
   (a) substance abuse counseling and treatment;
   (b) mental health counseling and treatment; and
   (c) education and counseling sessions about HIV, HIV transmission, and behavior change required to prevent transmission.

(13) The Division of Public Health shall conduct a partner notification program to assist in the notification and counseling of partners of HIV infected persons.

(14) Every pregnant woman shall be offered HIV testing by her attending physician at her first prenatal visit and in the third trimester. The attending physician shall test the pregnant woman for HIV infection, unless the pregnant woman refuses to provide informed consent pursuant to G.S. 130A-148(h). If there is no record at labor and delivery of an HIV test result during the current pregnancy for the pregnant woman, the attending physician shall inform the pregnant woman that an HIV test will be performed, explain the reasons for testing, and the woman shall be tested for HIV without consent using a rapid HIV test unless it reasonably appears that the test cannot be performed without endangering the safety of the pregnant woman or the person administering the test. If the pregnant woman cannot be tested, an existing specimen, if one exists that was collected within the last 24 hours, shall be tested using a rapid HIV test. The attending physician must provide the woman with the test results as soon as possible. However, labor and delivery providers who do not currently have the
capacity to perform rapid HIV testing are not required to use a rapid HIV test until January 1, 2009.

(15) If an infant is delivered by a woman with no record of the result of an HIV test conducted during the pregnancy and if the woman was not tested for HIV during labor and delivery, the fact that the mother has not been tested creates a reasonable suspicion pursuant to G.S. 130A-148(h) that the newborn has HIV infection and the infant shall be tested for HIV. An infant born in the previous 12 hours shall be tested using a rapid HIV test. However, providers who do not currently have the capacity to perform rapid HIV testing shall not be required to use a rapid HIV test until January 1, 2009.

(16) Testing for HIV may be offered as part of routine laboratory testing panels using a general consent which is obtained from the patient for treatment and routine laboratory testing, so long as the patient is notified that they are being tested for HIV and given the opportunity to refuse.

History Note: Authority G.S. 130A-135; 130A-144; 130A-145; 130A-148(h);
Temporary Rule Eff. February 1, 1988, for a period of 180 days to expire on July 29, 1988;
Eff. March 1, 1988;
Amended Eff. February 1, 1990; November 1, 1989; June 1, 1989;
Temporary Amendment Eff. January 7, 1991 for a period of 180 days to expire on July 6, 1991;
Amended Eff. May 1, 1991;
Recodified from 15A NCAC 19A .0201 (d) and (e) Eff. June 11, 1991;
Amended Eff. August 1, 1995; October 1, 1994; January 4, 1994; October 1, 1992;
Temporary Amendment Eff. February 18, 2002; June 1, 2001;
Amended Eff. November 1, 2007; April 1, 2005; April 1, 2003.
Appendix B

Statutory Authority for the N.C. HIV Control Measures

N.C.G.S. 130A-25

(a) Except as otherwise provided, a person who violates a provision of this Chapter or the rules adopted by the Commission or a local board of health shall be guilty of a misdemeanor.

(b) A person convicted under this section for violation of G.S. 130A-144(f) or G.S. 130A-145 shall not be sentenced under Article 81B of Chapter 15A of the General Statutes but shall instead be sentenced to a term of imprisonment of no more than two years and shall serve any prison sentence in McCain Hospital, Section of Prisons of the Division of Adult Correction, McCain, North Carolina; the North Carolina Correctional Center for Women, Section of Prisons of the Division of Adult Correction, Raleigh, North Carolina; or any other confinement facility designated for this purpose by the Secretary of Public Safety after consultation with the State Health Director. The Secretary of Public Safety shall consult with the State Health Director concerning the medical management of these persons.

(c) Notwithstanding G.S. 148-4.1, G.S. 148-13, or any other contrary provision of law, a person imprisoned for violation of G.S. 130A-144(f) or G.S. 130A-145 shall not be released prior to the completion of the person's term of imprisonment unless and until a determination has been made by the District Court that release of the person would not create a danger to the public health. This determination shall be made only after the medical consultant of the confinement facility and the State Health Director, in consultation with the local health director of the person's county of residence, have made recommendations to the Court.

(d) A violation of Part 7 of Article 9 of this Chapter or G.S. 130A-309.10(m) shall be punishable as a Class 3 misdemeanor.

N.C.G.S. 130A-135

A physician licensed to practice medicine who has reason to suspect that a person about whom the physician has been consulted professionally has a communicable disease or communicable condition declared by the Commission to be reported, shall report information required by the Commission to the local health director of the county or district in which the physician is consulted. The Commission shall declare confirmed HIV infection to be a reportable communicable condition.
N.C.G.S. 130A-143

All information and records, whether publicly or privately maintained, that identify a person who has AIDS virus infection or who has or may have a disease or condition required to be reported pursuant to the provisions of this Article shall be strictly confidential. This information shall not be released or made public except under the following circumstances:

1. Release is made of specific medical or epidemiological information for statistical purposes in a way that no person can be identified;
2. Release is made of all or part of the medical record with the written consent of the person or persons identified or their guardian;
3. Release is made for purposes of treatment, payment, research, or health care operations to the extent that disclosure is permitted under 45 Code of Federal Regulations §§ 164.506 and 164.512(i). For purposes of this section, the terms "treatment," "payment," "research," and "health care operations" have the meaning given those terms in 45 Code of Federal Regulations § 164.501;
4. Release is necessary to protect the public health and is made as provided by the Commission in its rules regarding control measures for communicable diseases and conditions;
5. Release is made pursuant to other provisions of this Article;
6. Release is made pursuant to subpoena or court order. Upon request of the person identified in the record, the record shall be reviewed in camera. In the trial, the trial judge may, during the taking of testimony concerning such information, exclude from the courtroom all persons except the officers of the court, the parties and those engaged in the trial of the case;
7. Release is made by the Department or a local health department to a court or a law enforcement official for the purpose of enforcing this Article or Article 22 of this Chapter, or investigating a terrorist incident using nuclear, biological, or chemical agents. A law enforcement official who receives the information shall not disclose it further, except (i) when necessary to enforce this Article or Article 22 of this Chapter, or when necessary to conduct an investigation of a terrorist incident using nuclear, biological, or chemical agents, or (ii) when the Department or a local health department seeks the assistance of the law enforcement official in preventing or controlling the spread of the disease or condition and expressly authorizes the disclosure as necessary for that purpose;
8. Release is made by the Department or a local health department to another federal, state or local public health agency for the purpose of preventing or controlling the spread of a communicable disease or communicable condition;
9. Release is made by the Department for bona fide research purposes. The Commission shall adopt rules providing for the use of the information for research purposes;
10. Release is made pursuant to G.S. 130A-144(b); or
(11) Release is made pursuant to any other provisions of law that specifically authorize or require the release of information or records related to AIDS.

**N.C.G.S. 130A-144**

(a) The local health director shall investigate, as required by the Commission, cases of communicable diseases and communicable conditions reported to the local health director pursuant to this Article.

(b) Physicians, persons in charge of medical facilities or laboratories, and other persons shall, upon request and proper identification, permit a local health director or the State Health Director to examine, review, and obtain a copy of medical or other records in their possession or under their control which the State Health Director or a local health director determines pertain to the (i) diagnosis, treatment, or prevention of a communicable disease or communicable condition for a person infected, exposed, or reasonably suspected of being infected or exposed to such a disease or condition, or (ii) the investigation of a known or reasonably suspected outbreak of a communicable disease or communicable condition.

(c) A physician or a person in charge of a medical facility or laboratory who permits examination, review or copying of medical records pursuant to subsection (b) shall be immune from any civil or criminal liability that otherwise might be incurred or imposed as a result of complying with a request made pursuant to subsection (b).

(d) The attending physician shall give control measures prescribed by the Commission to a patient with a communicable disease or communicable condition and to patients reasonably suspected of being infected or exposed to such a disease or condition. The physician shall also give control measures to other individuals as required by rules adopted by the Commission.

(e) The local health director shall ensure that control measures prescribed by the Commission have been given to prevent the spread of all reportable communicable diseases or communicable conditions and any other communicable disease or communicable condition that represents a significant threat to the public health. The local health department shall provide, at no cost to the patient, the examination and treatment for tuberculosis disease and infection and for sexually transmitted diseases designated by the Commission.

(f) All persons shall comply with control measures, including submission to examinations and tests, prescribed by the Commission subject to the limitations of G.S. 130A-148.

(g) The Commission shall adopt rules that prescribe control measures for communicable diseases and conditions subject to the limitations of G.S. 130A-148. Temporary rules prescribing control measures for communicable diseases and conditions shall be adopted pursuant to G.S. 150B-13.
(h) Anyone who assists in an inquiry or investigation conducted by the State Health Director for the purpose of evaluating the risk of transmission of HIV or Hepatitis B from an infected health care worker to patients, or who serves on an expert panel established by the State Health Director for that purpose, shall be immune from civil liability that otherwise might be incurred or imposed for any acts or omissions which result from such assistance or service, provided that the person acts in good faith and the acts or omissions do not amount to gross negligence, willful or wanton misconduct, or intentional wrongdoing. This qualified immunity does not apply to acts or omissions which occur with respect to the operation of a motor vehicle. Nothing in this subsection provides immunity from liability for a violation of G.S. 130A-143.

N.C.G.S. 130A-145

(a) The State Health Director and a local health director are empowered to exercise quarantine and isolation authority. Quarantine and isolation authority shall be exercised only when and so long as the public health is endangered, all other reasonable means for correcting the problem have been exhausted, and no less restrictive alternative exists.

(b) No person other than a person authorized by the State Health Director or local health director shall enter quarantine or isolation premises. Nothing in this subsection shall be construed to restrict the access of authorized health care, law enforcement, or emergency medical services personnel to quarantine or isolation premises as necessary in conducting their duties.

(c) Before applying quarantine or isolation authority to livestock or poultry for the purpose of preventing the direct or indirect conveyance of an infectious agent to persons, the State Health Director or a local health director shall consult with the State Veterinarian in the Department of Agriculture and Consumer Services.

(d) When quarantine or isolation limits the freedom of movement of a person or animal or of access to a person or animal whose freedom of movement is limited, the period of limited freedom of movement or access shall not exceed 30 calendar days. Any person substantially affected by that limitation may institute in superior court in Wake County or in the county in which the limitation is imposed an action to review that limitation. The official who exercises the quarantine or isolation authority shall give the persons known by the official to be substantially affected by the limitation reasonable notice under the circumstances of the right to institute an action to review the limitation. If a person or a person's representative requests a hearing, the hearing shall be held within 72 hours of the filing of that request, excluding Saturdays and Sundays. The person substantially affected by that limitation is entitled to be represented by counsel of the person's own choice or if the person is indigent, the person shall be represented by counsel appointed in
accordance with Article 36 of Chapter 7A of the General Statutes and the rules adopted by the Office of Indigent Defense Services. The court shall reduce or terminate the limitation unless it determines, by the preponderance of the evidence, that the limitation is reasonably necessary to prevent or limit the conveyance of a communicable disease or condition to others.

If the State Health Director or the local health director determines that a 30-calendar-day limitation on freedom of movement or access is not adequate to protect the public health, the State Health Director or local health director must institute in superior court in the county in which the limitation is imposed an action to obtain an order extending the period of limitation of freedom of movement or access. If the person substantially affected by the limitation has already instituted an action in superior court in Wake County, the State Health Director must institute the action in superior court in Wake County or as a counterclaim in the pending case. Except as provided below for persons with tuberculosis, the court shall continue the limitation for a period not to exceed 30 days if it determines, by the preponderance of the evidence, that the limitation is reasonably necessary to prevent or limit the conveyance of a communicable disease or condition to others. The court order shall specify the period of time the limitation is to be continued and shall provide for automatic termination of the order upon written determination by the State Health Director or local health director that the quarantine or isolation is no longer necessary to protect the public health. In addition, where the petitioner can prove by a preponderance of the evidence that quarantine or isolation was not or is no longer needed for protection of the public health, the person quarantined or isolated may move the trial court to reconsider its order extending quarantine or isolation before the time for the order otherwise expires and may seek immediate or expedited termination of the order. Before the expiration of an order issued under this section, the State Health Director or local health director may move to continue the order for additional periods not to exceed 30 days each. If the person whose freedom of movement has been limited has tuberculosis, the court shall continue the limitation for a period not to exceed one calendar year if it determines, by a preponderance of the evidence, that the limitation is reasonably necessary to prevent or limit the conveyance of tuberculosis to others. The court order shall specify the period of time the limitation is to be continued and shall provide for automatic termination of the order upon written determination by the State Health Director or local health director that the quarantine or isolation is no longer necessary to protect the public health. In addition, where the petitioner can prove by a preponderance of the evidence that quarantine or isolation was not or is no longer needed for protection of the public health, the person quarantined or isolated may move the trial court to reconsider its order extending quarantine or isolation before the time for the order otherwise expires and may seek immediate or expedited termination of the order. Before the expiration of an order limiting the freedom of movement of a person with
tuberculosis, the State Health Director or local health director may move to continue the order for additional periods not to exceed one calendar year each.

N.C.G.S. 130A-148

(a) For the protection of the public health, the Commission shall adopt rules establishing standards for the certification of laboratories to perform tests for Acquired Immune Deficiency Syndrome (AIDS) virus infection. The rules shall address, but not be limited to, proficiency testing, record maintenance, adequate staffing and confirmatory testing. Tests for AIDS virus infection shall be performed only by laboratories certified pursuant to this subsection and only on specimens submitted by a physician licensed to practice medicine. This subsection shall not apply to testing performed solely for research purposes under the approval of an institutional review board.

(b) Prior to obtaining consent for donation of blood, semen, tissue or organs, a facility or institution seeking to obtain blood, tissue, semen or organs for transfusion, implantation, transplantation or administration shall provide the potential donor with information about AIDS virus transmission, and information about who should not donate.

(c) No blood or semen may be transfused or administered when blood from the donor has not been tested or has tested positive for AIDS virus infection by a standard laboratory test.

(d) No tissue or organs may be transplanted or implanted when blood from the donor has not been tested or has tested positive for AIDS virus infection by a standard laboratory test unless consent is obtained from the recipient, or from the recipient's guardian or a responsible adult relative of the recipient if the recipient is not competent to give such consent.

(e) Any facility or institution that obtains or transfuses, implants, transplants, or administers blood, tissue, semen, or organs shall be immune from civil or criminal liability that otherwise might be incurred or imposed for transmission of AIDS virus infection if the provisions specified in subsections (b), (c), and (d) of this section have been complied with.

(f) Specimens may be tested for AIDS virus infection for research or epidemiologic purposes without consent of the person from whom the specimen is obtained if all personal identifying information is removed from the specimen prior to testing.

(g) Persons tested for AIDS virus infection shall be notified of test results and counseled appropriately. This subsection shall not apply to tests performed by or for entities governed by Article 39 of Chapter 58 of the General Statutes, the Insurance Information and Privacy Protection Act, provided that said entities comply with the notice requirements thereof.

(h) The Commission may authorize or require laboratory tests for AIDS virus infection when necessary to protect the public health.
A test for AIDS virus infection may also be performed upon any person solely by order of a physician licensed to practice medicine in North Carolina who is rendering medical services to that person when, in the reasonable medical judgment of the physician, the test is necessary for the appropriate treatment of the person; however, the person shall be informed that a test for AIDS virus infection is to be conducted, and shall be given clear opportunity to refuse to submit to the test prior to it being conducted, and further if informed consent is not obtained, the test may not be performed. A physician may order a test for AIDS virus infection without the informed consent of the person tested if the person is incapable of providing or incompetent to provide such consent, others authorized to give consent for the person are not available, and testing is necessary for appropriate diagnosis or care of the person.

An unemancipated minor may be tested for AIDS virus infection without the consent of the parent or legal guardian of the minor when the parent or guardian has refused to consent to such testing and there is reasonable suspicion that the minor has AIDS virus or HIV infection or that the child has been sexually abused.

(i) Except as provided in this section, no test for AIDS virus infection shall be required, performed or used to determine suitability for continued employment, housing or public services, or for the use of places of public accommodation as defined in G.S. 168A-3(8), or public transportation.

Further it shall be unlawful to discriminate against any person having AIDS virus or HIV infection on account of that infection in determining suitability for continued employment, housing, or public services, or for the use of places of public accommodation, as defined in G.S. 168A-3(8), or public transportation.

Any person aggrieved by an act or discriminatory practice prohibited by this subsection relating to housing shall be entitled to institute a civil action pursuant to G.S. 41A-7 of the State Fair Housing Act. Any person aggrieved by an act or discriminatory practice prohibited by this subsection other than one relating to housing may bring a civil action to enforce rights granted or protected by this subsection.

The action shall be commenced in superior court in the county where the alleged discriminatory practice or prohibited conduct occurred or where the plaintiff or defendant resides. Such action shall be tried to the court without a jury. Any relief granted by the court shall be limited to declaratory and injunctive relief, including orders to hire or reinstate an aggrieved person or admit such person to a labor organization.

In a civil action brought to enforce provisions of this subsection relating to employment, the court may award back pay. Any such back pay liability shall not accrue from a date more than two years prior to the filing of an action under this subsection. Interim earnings or amounts earnable with reasonable diligence by the aggrieved person shall operate to reduce the back pay
otherwise allowable. In any civil action brought under this subsection, the court, in its discretion, may award reasonable attorney's fees to the substantially prevailing party as a part of costs.

A civil action brought pursuant to this subsection shall be commenced within 180 days after the date on which the aggrieved person became aware or, with reasonable diligence, should have become aware of the alleged discriminatory practice or prohibited conduct.

Nothing in this section shall be construed so as to prohibit an employer from:

1. Requiring a test for AIDS virus infection for job applicants in preemployment medical examinations required by the employer;
2. Denying employment to a job applicant based solely on a confirmed positive test for AIDS virus infection;
3. Including a test for AIDS virus infection performed in the course of an annual medical examination routinely required of all employees by the employer; or
4. Taking the appropriate employment action, including reassignment or termination of employment, if the continuation by the employee who has AIDS virus or HIV infection of his work tasks would pose a significant risk to the health of the employee, coworkers, or the public, or if the employee is unable to perform the normally assigned duties of the job.

(j) It shall not be unlawful for a licensed health care provider or facility to:

1. Treat a person who has AIDS virus or HIV infection differently from persons who do not have that infection when such treatment is appropriate to protect the health care provider or employees of the provider or employees of the facility while providing appropriate care for the person who has the AIDS virus or HIV infection; or
2. Refer a person who has AIDS virus or HIV infection to another licensed health care provider or facility when such referral is for the purpose of providing more appropriate treatment for the person with AIDS virus or HIV infection.
Appendix C

Informed Consent for Participation in the HIV Control Measures Study

This study will be completed by Erin Close, a student at Duke University’s Global Health Institute and School of Law. This research will be used to complete her Master’s thesis.

This study will interview key informants regarding their experiences with the implementation of North Carolina’s HIV Control Measures and their perceptions of the same.

If you agree to participate in the study, the interview will last between 30 minutes and one hour. The interview will be electronically recorded. The transcripts of our interview will be seen only by me and my thesis committee. I will identify you by your position and organization in my thesis. With your permission, I would also like to attribute quotes directly to you.

Even if I don’t quote you, you may still be identified, so if you would rather not be identified in my thesis, I would like to discourage you from participating.

Participation in this study is voluntary: you do not have to participate if you do not want to, and if you do decide to participate, you can skip any questions you do not want to answer and you may stop the interview at any time. If at any point, you wish to speak off the record, just let me know and I will turn off the recorder. If you chose to withdraw from the study, the information you have provided will not be included in the research project.

At the end of the interview, you will receive a thank you Starbucks gift card (valued at $5.00). If you would like to receive a gift card, you will have to provide your social security number and address on a payment verification form, which will be submitted to the Duke University Accounting Office for tax purposes. The information you provide on the form will never be linked to this consent form or your interview responses. If you don't want to provide your information, you can still be in the study but you will not receive payment.

If you have any questions regarding the details of this study, feel free to ask them now. You can also ask any questions you have during or after the interview. You can contact me at erin.m.close@gmail.com or 917-842-7884, or my advisor, Dr. Lynne Messer at lynne.messer@duke.edu or 919-613-5462.
You can also contact the Duke University Institutional Review Board for any questions about your rights as a participant in my research at 919-684-3030 or ors-info@duke.edu.

If you would like to participate in this study, please sign below.

______________________________________________  ________________
Signature of Subject                           Date

______________________________________________  ________________
Signature of Person Obtaining Consent         Date
Appendix D

Recruitment Emails

Below is an example of my recruitment email. It was changed for each “profession” but the only thing substantively changed was the 3rd paragraph, regarding the reasons that a certain person may be interested in participating. This part is bolded in the example email below.

Dear ____:

I am a 3rd year joint degree student pursuing both a J.D. and a M.Sc. in Global Health at the Global Health Institute. As part of my graduation requirement, I am completing a Masters Thesis. It is important to me that my thesis is reflective of both my courses of studies, and so I am conducting a qualitative exploration of the North Carolina HIV Control Measures. I have focused much of my upper-level time on HIV/AIDS issues, and participated in the Duke Legal Clinic (which provides legal services to indigent HIV-positive individuals in North Carolina) last semester.

My study will interview key informants regarding their experiences with the implementation of North Carolina’s HIV Control Measures and their perceptions of the same. I am hopeful that this research will be useful in the public health policy arena in North Carolina, as there has been little research done on the manner in which the control measures fulfill the public health goals for which they were implemented.

If you have been practicing in North Carolina for more than two years, and spend more than half of your time serving HIV-positive patients, I would greatly appreciate if you would be willing to be interviewed for this project. I expect the interviews to last between 30 minutes and an hour, and am happy to work around your schedule, and to meet you wherever is most convenient for you.

If you would be willing to participate, please contact me back via email (or phone, if that is preferable – 917-842-7884) and we can set up a time to speak.

Thank you in advance,
Erin Close
Appendix E

Interview Questions/Prompts for Physicians

1. How long have you been working as an Infectious Disease Doctor?
2. What percentage of your time is spent working with HIV-positive individuals?
3. What training have you received regarding the control measures and how to explain them to patients?
4. Can you tell me about your standard procedure for telling a new HIV+ patient about their diagnosis?
   a. Could you demonstrate to me how you describe the control measures to these patients? (Pretend I am a newly diagnosed patient)
5. Could you demonstrate to me how you counsel a newly diagnosed patient on spousal notification? (Again, pretend I am a newly diagnosed patient)
   a. How often have you had a patient refuse to give consent to notify their spouse?
   b. Do you solicit the names of other potential contacts from the patient? (This is not required by the control measures)
6. What do you tell patients regarding the fact that they will be contacted by a disease intervention specialist as a result of their diagnosis?
7. Do your patients speak with you afterwards about their experience with the DIS?
   a. Could you describe your sense of a typical patient’s emotional reaction to this process?
8. In follow up appointments, how do you counsel your patients regarding continued adherence to the control measures?
   a. Condom use
   b. Status disclosure to partners
9. Do you ever hear from your patients that they are not adhering to the control measures?
   a. What is your reaction in this situation?
   b. Section 5 of the control measures requires that “The attending physician shall notify the local health director when the physician, in good faith, has reasonable cause to suspect a patient infected with HIV is not following or cannot follow control measures and is thereby causing a significant risk of transmission…”
   c. What, in your opinion, constitutes “reasonable cause”?
   d. How often, if ever, have you had to report a patient to the health department because the risk of transmission they pose to another?
10. If you have noticed a change in your patients’ behavior following the conversation about the control measures, to what do you attribute that change?
   a. The threat of jail time?
   b. The diagnosis itself?

11. Is there any other information (anecdotes, etc.) you think I should know regarding the control measures and this process that might help me better understand the average patient’s experience with new diagnosis/the control measures/DIS?

Interview Questions/Prompts for Disease Intervention Specialists

1. Can you tell me about your standard procedure for your first contact with a newly diagnosed HIV-positive individual?
   a. Phone? Letter? In person?
   b. Do you try to set up a meeting?

2. How do you explain your role, and the control measures, when you do meet the patient?
   a. Pretend I am a newly diagnosed patient and walk me through the process

3. How do you solicit partner names from the patient?
   a. If you feel that they are withholding partner information, how do you attempt to get them to disclose this to you?

4. Can you outline your educational and employment background?
   a. What level of education? (and what degree specialization)
   b. What previous jobs have you held?

5. What type of training did you get as part of your DIS position?
   a. Did you shadow other DIS?
   b. Is there some sort of guiding manual that is used?

6. Is there anything else (anecdotes, etc.) you have regarding the control measures and this process that might help me better understand the experiences you have in your job?

Interview Questions/Prompts for Other Key Informants

1. What is your profession?

2. What is your involvement with the HIV+ community/HIV policy in North Carolina?

3. How long have you been involved with the HIV+ community/HIV policy in North Carolina?

4. What experience do you have implementing or studying the HIV Control Measures?

5. Have you spoken with HIV+ individuals afterwards about their experience with the DIS and the control measures?
   a. Could you describe your sense of a typical individual’s emotional reaction to this process?
6. Do you ever hear from individuals that they are not adhering to the control measures?
   a. What is your reaction in this situation?
7. If you have noticed a change in behavior resulting from the control measures, to what do you attribute that change?
   a. The threat of jail time?
   b. The diagnosis itself?
8. Is there any other information (anecdotes, etc.) you think I should know regarding the control measures and this process that might help me better understand the average patient’s experience with new diagnosis/the control measures/DIS?
Appendix F

DIS Training Materials

DIS TRAINING INTRODUCTION

During your first year as a DIS, you will be expected to learn a tremendous amount of material related to STD’s and disease intervention. You will also learn and observe various interview techniques to assist you in dealing with all types of people with all types of problems and emotions.

Due to the importance of your position as a DIS, the training is extremely specialized. The following information will help you anticipate what your first 12 months as a DIS will look like regarding training.

State Orientation will walk you through personnel issues regarding your insurance, benefits and other employee related issues. On-line

Orientation with Staff Development Specialist will familiarize you with the specifics of your position as a DIS, including trainings. Ongoing

State Course Requirements such as ICS-100, ICS-200, ICS-700 (bioterrorism response systems) and your role as a public health employee; HIPAA; Workplace harassment; Fire and Life Safety; IRB. On-line

DIS Modules 15 modules will educate and test you on STD and disease intervention information vital to your position as a DIS.

Counseling Testing & Referral (CTR) will teach you the specifics of the client-centered approach of HIV counseling and testing. 2-day course

Phlebotomy & Bloodborne Pathogens will teach you how to perform venipuncture and educate you on the safety of handling potentially contaminated bodily fluids. 2-day course

Visual Case Analysis (VCA) will enhance your knowledge regarding module 12. 2-day course

Fundamentals of Disease Intervention will teach you the specific interview models for HIV and Syphilis that a DIS must follow. 2-week course

Oraquick Training will teach you how to administer the rapid HIV test to clients. 2-hour course.
**Advanced Case Management** will enhance your STD and disease intervention knowledge from prior trainings. 2-day course.

*ICS Basic training will teach you the language and basic structure of Incident Command.

*Throughout these first 12 months, you will be mentored in the field and in the office. These mentors will model all DIS activities regarding interviews, field work and case management. Not only will you observe, but you will be observed once the FDI course is completed successfully.

**NO DIS WILL CONDUCT INTERVIEWS ALONE WITHOUT GRADUATING FROM THE FDI COURSE AND BEING FORMALLY APPROVED BY A MEMBER OF THE MANAGEMENT TEAM!**
FIELD SERVICES DIS TRAINING PLAN
0 – 12 MONTHS

OSHA
CTR
VENIPUNCTURE
CONFIDENTIALITY
NEW DIS ORIENTATION WITH MANAGEMENT

TRAINING PROCESS ORIENTATION

FIELD TEST & MEDIKIS
Ass Turner

IDENTIFY DISEASE INTERVENTION

FIELD RISK DISSUSION PLAN
Trains & Supervisor

STIMIS

SUPERVISED FIELDWORK
HIV/Outpatient Office

SOCIAL-NURSING NETWORK TRAINING

ADVANCED DISEASE INTERVENTION

EXIT DIS

FOLLOWUP PLAN
Trains & Supervisor

MEET WITH FIELD SERVICES MANAGER

FIELD OBSERVATION
Mentor/Supervisor
References


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Statutes

N.C.G.S. 130A-25
N.C.G.S. 130A-135
N.C.G.S. 130A-143.
N.C.G.S. 130A-144.
N.C.G.S. 130A-148

Regulations

10A NCAC 41A .0101, “Reportable Diseases and Conditions.”
10A NCAC 41A.0202, Control Measures – HIV, 12.

Case Law