The Factors that Influence Data Utilization in Decision-Making: The Case of HIV/AIDS Programs in Mexico

By

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A dissertation submitted in partial satisfaction of the requirements for the degree of

Doctor of Public Health

in the

Graduate Division

of the

University of California, Berkeley

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Spring 2011

Abstract

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In Mexico, as in many other countries, HIV/AIDS strategies are developed at the federal level and implemented at the state level. Local programs are expected to use data, in particular surveillance data, to drive their decisions on programmatic activities and prioritize populations with which the program will engage. Since the early 1980s Mexico has engaged a complex and consistent strategy to address HIV and as a result, a great deal of data is available to help target prevention efforts. However, data utilization varies by state due to a number of factors that influence the process. This dissertation uses the case of state HIV/AIDS programs in Mexico to identify and explore the factors that influence data utilization and evaluate their effect on these programs. Three distinct papers are used to explore this topic.

The first paper is a literature review that provides an overview of factors that have been previously identified to influence data and research uptake by decision-makers. These factors are sorted into three categories—macro political, resource and data characteristics—to develop a model for influencing decisions. This model is then superimposed over the cycle for surveillance data in order to clearly ascertain the effect these factors have on data utilization. In the second paper the model developed in the first paper is evaluated through a study in four state programs in Mexico. Interviews and a survey were conducted to assess how the influence factors facilitate and impede data utilization at the local level. Issues around communication, decision-making power, budgeting, data quality and dissemination were the primary concerns identified. The third and final paper explores decision space in these state programs. Specifically, this paper reviews the negative side effects that enforcing an existing policy against sharing antiretroviral drugs between states has had on the decision space of programs at the local level.

The results from this research show that in addition to the expected barriers to using data for decision-making, there are also a variety of subtle forces affecting local actors that also need to be taken into account if data utilization is to be improved. One of the main contributions of this study is the approach of studying macro political, resource and data factors simultaneously in order to assess the combined effect they have on decision-makers. This study also helps identify potential areas that both local and national-level actors can leverage to move towards data-driven programming, such as improving local capacity for data analysis and strategic changes to current data dissemination practices. Future research directions include additional

comparative studies in Mexico as well as in other middle- and lower-income countries, further explorations of constrained decision space and how it affects program performance and an evaluation of the relative value of experiential knowledge in settings were data are absent or unreliable.

DEDICATION

To LKNY, none of this would have been possible without you.

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ABBREVIATIONS

Abbreviation	English	Spanish
AIDS	Acquired Immune Deficiency Syndrome	
ART	Anti-retroviral therapy	
CENSIDA	National Center for Prevention and Control of HIV/AIDS	Centro Nacional para la Prevención y Control del VIH/SIDA
COESIDA	State Council for AIDS Prevention	Consejo Estatal para la Prevención del SIDA
CONASIDA	National Council for AIDS Prevention	Consejo Nacional para la Prevención del SIDA
DGE	General Epidemiology Directorate	Dirección General de Epidemiolgía
FPGC	Fund for Protection against Catastrophic Expenses	Fondo de Protección contra Gastos Catastróficos
FSW	Female commercial sex worker	
HIV	Human Immunodeficiency Virus	
IDU	Injecting drug user	
IMSS	Mexican Institute for Social Security	Instituto Mexicano del Seguro Social
INSP	National Public Health Institute	Instituto Nacional de Salud Pública
IRB	Institutional Review Board	
ISSSTE	Social Security and Services Institute for Government Workers	Instituto de Seguridad y Servicios Sociales para Trabajadores del Estado
MIC	Middle-income country	
MSM	Men who have sex with men	
MSW	Male commercial sex worker	
NGO	Non-governmental organization	
PLWHA	Persons living with HIV/AIDS	
SESA	State Health Secretariat	Secretaría Estatal de Salud
SSA	Ministry of Health	Secretaría de Salud
STI	Sexually-transmitted infection	

ACKNOWLEDGEMENTS

I would first like to acknowledge and thank all of those individuals who gave me their time and attention to participate in this study. The men and women that work in and with state HIV/AIDS programs in Mexico face an uphill battle every day and I hope that this dissertation does its part in characterizing their struggles. Their commitment to people living with HIV is palpable in their work, their conversations and their desire to continuously improve their efforts in the community.

Second, I want to recognize the support, mentoring and guidance that I received from my dissertation committee members. From the first moment I met Ann Keller I knew I found a kindred spirit in bridging the divide between political science and public health and I was not disappointed. In her role as dissertation chair, she showed invaluable commitment to me and to my research. Our collaboration has improved my critical thinking, my writing and brought be back from the ledge more than once. George Rutherford brought essential insight from the front lines of HIV work and made sure that my writing was grounded in that experience. Through his wit and sharp mind George always managed to pinpoint the implications of my work and encouraged me to highlight them. Finally, Xiaoxia Newton's incredible wealth of experience in evaluation provided the additional and necessary lens with which to assess my dissertation work. Between them, my committee members have pushed me to a whole new level of public health research and for that I owe them a huge debt of gratitude.

Third, I must thank my friends and family for their support throughout this long and arduous process. My friends within the DrPH program were the first sounding boards when I was just starting to develop my dissertation topic. In particular my cohort friends Jenica and Kristina have given me the immense amounts of support, understanding and motivation necessary to come through the other side in one piece. My friends outside of the program are in a class by themselves, especially Emily and Danny. At times, they have been essentially abandoned and yet still answer my calls when I come up for air. For you, your sense of humor and your support I will be eternally grateful.

As for my family, my parents and siblings have been one of my major pillars of strength. My mother's commitment to continually evolving through education and new experiences is an inspiration. She has always been one of the first people with whom I discuss a new idea and I hope that never changes. At times, my mom has had a clearer vision on what I was trying to accomplish with this research than I have and thankfully, she always put me back on track. My father knows and understands what drives his children better than I think we have ever acknowledged. His advice early on in my career to stay away from lab-centered work and focus on working with people was way more insightful than I realized at the time. I cherish the interests we share and I hope to share them for many years to come. To my siblings Maite, Bernardo, Margie y Paulina: ustedes han sido los mejores hermanos que una hermanita hubiera podido querer. Sin ustedes, su apoyo, su sentido de humor y nuestras vacaciones juntos no estaría aquí terminando mi tesis. Los quiero mucho.

Finally, I must single out my husband, Mike. His love and support have carried me through the some of the most difficult moments I ever experienced in research. I have always felt he was as committed to my getting this degree as I was and that support has made a huge difference. He never fails to show his pride in my work and accomplishments, even when it embarrasses me. Mike, you have been the best partner that I could ever hope to have. You have

known just how to support me at every step of the way. It makes me incredibly happy that we can continue our journey together beyond this point in our lives. On to new adventures!

INTRODUCTION

> *"If we are capturing [surveillance data] of interest, I think that they should be applied, effectively. If not, they lose the importance they have." – Mexican State Government Official, 2004*

This statement, made by an official in a state HIV/AIDS program in Mexico, encompasses a modern-day quandary: we should be using the data we have to make our programs better. So, are we using data? What helps or hinders us from using data? Why do some local actors seem to do better when using their data than others? How much discretion do program officials need to make the best decisions?

Early approaches to studying decision-making adopted a rationalist approach. They suggested that decision-makers considered the existing policy, assessed the gaps and set new goals and then developed a policy to meet the new goals. However, mid-20th century researchers began to recognize that decision-making is rarely a linear process, in part due to the complex environmental factors that influence public organizations. It is in this multifaceted context where local HIV/AIDS programs reside and make decisions about how the program will operate.

Strategies to address HIV/AIDS often are planned at national or centralized levels, while much of the implementation activities take place at sub-national levels, such as states, districts and municipalities, especially for prevention. Local programs and staff are expected to translate nationally-set strategies to their local contexts because local epidemic profiles can vary widely. Optimal translation integrates surveillance data into the prevention planning process and adapts prevention activities to the local epidemic profile. This exercise in translation is predicated on the idea that local decision-makers have access to reliable data about their epidemic and can use the data effectively. However, the use of data to guide local decision-making is complicated by a number of potential contingencies outside of the surveillance cycle itself which are often subtler and harder to identify than expected.

HIV/AIDS surveillance data can help local programs target their efforts so that they can meet the needs of the people who are already infected and those who are most at risk for contracting HIV. Mexico has a considerable amount of surveillance data with the potential to be used to for prioritizing populations for intervention but these data are not being utilized to their fullest potential at the local level. There are a number of factors that influence the deceptively simple process of prioritization. Some factors become barriers and others facilitators to the data utilization process and it is necessary to identify and address all of them.

Given the limited information about how data incorporation translates in local, on-the-ground settings, there are different suggestions about how data utilization takes place. Lindblom's incrementalism and Weiss and Bucuvalas' truth and utility tests suggest that decision-makers value data utilization and implement various tactics to achieve it.[1-3] Others have proposed that decisions are based solely on resources or exercising power in the organizational system. These and other studies on data and research utilization have restricted their focus to a specific kind of factor, such as political, resource or data issues. However, since these factors all have influence over the data utilization process as well as on the decision itself, my research has focused on all three types of factors together. In this dissertation, I use the case of state HIV/AIDS programs in Mexico to explore comprehensively the macro political, resource and

data characteristic factors that influence data utilization in decision-making, identify how these factors impede and facilitate data utilization and evaluate the effect of discretion, or decision space, on these programs.

MEXICO, DECENTRALIZATION AND HIV

Mexico is a middle-income country (MIC) with a concentrated HIV/AIDS epidemic. The prevalence rate in the general population is fairly low at 0.3%, but there are higher concentrations of disease in certain sub-populations, such as men who have sex with other men (MSM) and female commercial sex workers (FSW).[4] Mexico's efforts to combat the HIV/AIDS epidemic have been multi-faceted, consistent and ongoing since the early 1980s. Much of the data necessary to focus prevention efforts and, consequently avert future infections, are already available in Mexico. Nevertheless, there is considerable variability in how state-level HIV/AIDS programs use biological and behavioral surveillance data. Given similar resources and surveillance data, utilization varies by state, influencing the performance of prevention programs. In order to improve surveillance data utilization in HIV/AIDS programs, especially prevention programs, it is essential to identify and understand the factors that influence surveillance data utilization as priorities are set in prevention programs at the local level.

Healthcare decentralization efforts in Mexico and elsewhere have shifted many tasks from a central level to the local levels, bringing to bear a "principal-agent" model.[5] Under principal-agent, the principal is an actor with specific objectives and the agent is the actor whose role it is to implement the activities needed to meet those objectives. In Mexico after decentralization, the Ministry of Health (*Secretaría de Salud, SSA*) with its objective to improve health for all Mexicans plays the role of principal. This role is further enhanced by the regulatory and stewardship responsibilities of the *SSA*. The individual states then become the agents responsible for managing healthcare delivery.

For HIV/AIDS the *SSA*'s role as principal is performed by the National Center for Prevention and Control of HIV/AIDS (*Centro Nacional para la Prevención y Control del VIH/SIDA, CENSIDA*) through activities such as antiretroviral treatment (ART) guidelines and procurement, nationwide prevention campaigns and research projects. State HIV/AIDS programs are the agents whose responsibilities include collecting and submitting surveillance data, managing treatment and care for persons receiving antiretroviral drugs and prevention activities for at-risk populations in the state. Within its role as principal, *CENSIDA* maintains a relationship with state programs to ensure that regulatory guidelines around treatment and prevention are being met. Meanwhile, state programs are tasked with providing services while concurrently navigating political, social and economic conditions specific to their local environment. In this context, state programs are mediating two sets of goals: *CENSIDA*'s (i.e. meeting regulations) and their own (i.e. addressing local population needs while taking politics into consideration). Under these circumstances, it is critically important to assess the factors that are influencing how state programs make decisions, especially when they are determining their priorities for prevention.

HIV/AIDS is an ideal condition for this study for several reasons. First, HIV is transitioning from a strictly infectious disease to chronic one in many places, calling for both treatment *and* prevention funding to be spent towards stemming its spread. Consequently, the amount of resources that must be directed towards it are increasing exponentially. Second, although HIV has received a great deal of attention and funding in the last 10 years, many countries are funding their efforts on their own without the assistance of international donors.

Lastly, there have been substantial data collection and research efforts around HIV/AIDS with a vision to ensure that data are driving programmatic decision-making.

Mexico presents an illustrative case because it is a MIC with a decades-long, fairly stable government and health infrastructure. As a country with a concentrated HIV epidemic, it has been funding all of its own HIV/AIDS efforts, including a consistent surveillance system for HIV that generates data that could and should be used at the state level. Finally, Mexico is a large, demographically diverse country. It contains a considerable range of liberal and conservative viewpoints and a variety of rural, peri-urban and urban communities and landscapes. Mexico also represents a society where populations that are traditionally most at-risk for infection, such as homosexual men, sex workers and drug users, are heavily stigmatized, and other marginalized populations at-risk, like indigenous people and migrants, are unaware of their risks for HIV.

DISSERTATION OVERVIEW

In addition to an extensive literature review, primary data were collected for this study in four states in Mexico. Following a brief pilot study, I spent six weeks in Mexico in 2010 administering a survey (see Appendix) and conducting interviews with individuals working in or with state HIV/AIDS programs in a number of capacities, including program management, surveillance, patient care and activity implementation. The information generated during this time has provided the rich source material that drives this dissertation.

This dissertation is organized into three distinct papers. These papers follow my intellectual transition on the approach to data utilization in decision-making. While conducting this research, I progressed from focusing on the role and importance of incorporating data in decision-making to recognizing the role that programmatic discretion has on how programs function. This transition is reflected in the sequence of papers presented in this dissertation, with the first two papers focused on data utilization and the third focused on decision space. Furthermore, I use the conclusion to explore and question an idea that arose from this research regarding how experiential knowledge can be substituted in place of data when making decisions.

The first paper examines how incorporating surveillance data into decision-making is influenced by three broad categories of factors: macro political, resource and data characteristics. Each category is explored in detail in order to develop a model that depicts how all of these factors influence decision-makers and decisions themselves. The model of factors is then superimposed over the cycle for surveillance data with the aim of concretizing the effect that macro political, resource and data issues have on different decision points in surveillance data utilization.

In the second paper, I used the models developed in Paper 1 to explore how these factors impede and facilitate surveillance data utilization in state HIV/AIDS programs in Mexico. I start by describing the Mexican health system as well as Mexico's response to HIV. This is followed by presenting the barriers and facilitators to data utilization that arose from the surveys and interviews organized according to the categories from Paper 1.

The third and final paper presents an unexpected theme that emerged during data collection: the unintended consequences that enforcing an existing policy has had on state programs. A policy against sharing antiretroviral drugs between states has been in place for years but only recently has it been strictly enforced. I use a "decision space" approach[5] to analyze the effect this policy has had on the discretion that state programs can exercise and its

significance to gains garnered through decentralization. This last paper fits within the larger framework on decision-making because greater discretion at the local level results in greater programmatic effectiveness. However, the enforcement of the "no sharing" policy undermines the goal of localized decision-making born out of the decentralization of the health system.

Lastly, in addition to summarizing the research findings, I conclude with a critique that arose through this research process. Not fully considered in the literature, or in my own research, is the potential value of experience in lieu of data when program officials make decisions about how to target their program's activities. I use this section to explore this idea as well as to propose future areas for research and intervention aimed at improving data utilization in decision-making.

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CHAPTER 1: USING SURVEILLANCE DATA TO IMPROVE DECISION-MAKING IN A POLITICAL ENVIRONMENT

Surveillance in the context of public health is most commonly defined as the "ongoing systematic collection, analysis, and interpretation of outcome-specific data for use in the planning, implementation, and evaluation of public health practice."[6] The three main activities that guide surveillance are identified as (1) data collection, (2) data analysis and (3) dissemination/feedback.[7-9] However, descriptions of surveillance systems are often lacking the key aspect of infusing data into the decisions that determine programmatic activities. The entire surveillance data cycle, but especially the missing step of "data translation", is influenced by the complexity of the organization, political, and social environment that surrounds health programs. This is especially true in HIV/AIDS programs where, for example, managers have to contend with issues of stigma towards high-risk populations in addition to more common barriers, such as insufficient resources.

Strategies to address HIV/AIDS often are planned at national or centralized levels, while much of the implementation activities take place at sub-national levels, such as states, districts and municipalities, especially for prevention. Local programs and staff are expected to translate nationally-set strategies to their local contexts. Optimal translation integrates surveillance data into the prevention planning process and adapts prevention activities to the local epidemic profile. However, the use of data to guide local decision-making is complicated by a number of potential contingencies outside of the surveillance cycle itself which are often subtler and harder to identify than expected. In order for data translation to take place effectively, we need to take into consideration all of the factors that influence the decision-making process and identify how they affect data utilization. This paper will present a comprehensive view of the factors that influence the surveillance data cycle through the lens of decision-making in a political environment. To this end, I will use a political science perspective to shed light on the decision-making process and the multiple sources of influence that affect it. I will conclude by juxtaposing the factors that influence decision-making over the data utilization cycle and examine their interplay and its implications for future efforts in data utilization.

DECISION-MAKING IN A POLITICAL ENVIRONMENT

Early theories on decision-making suggested that, when taking on the challenge of changing a social policy, decision-makers followed a set path: consider the existing policy, set new goals and then develop a new policy that would achieve those goals. Starting in the mid-20th century, social scientists began to challenge that rationalistic model with more complex visions. In this section, I present three approaches to decision-making taken from political science that describe the complex political environments that surround public organizations and that can illuminate the context in which surveillance data can play a role.

Charles Lindblom provides the first alternative view on how decisions are made, which is more realistic to the settings of public sector organizations.[1] Lindblom steered away from the "Rational-Comprehensive" model towards one he called "Successive Limited Comparisons" where decision-makers start by comparing a limited number of possible options, each of which may only represent a small change from the *status quo.* Lindblom argues that policy making was

likely to be **incremental** rather than comprehensive and that learning would take place over time as decision makers evaluated the outcomes associated with a given policy change.[1] Because social issues are so complex and common objectives are hard to identify, no one administrator can gather information on all of the factors that influence the decision at hand much less understand it. Thus, instead of thinking of changing policy drastically, administrators are forced to focus their attention on incremental changes in policy. With this approach, the decision-maker only has to analyze the details by which the existing policy and suggested alternative policies differ. An additional benefit is that by avoiding significant changes, successive incremental changes in policy limit the chances of serious mistakes.[1] Lindblom further argues that, while the process is not usually linear, it is systematic.[1]

The second approach to decision-making focuses on the **constraints** that decision-makers experience. Although it is focused on the inner workings of the public sector in the United States, James Q. Wilson's book on bureaucracy has some insights that are applicable across the board. Of particular interest is Wilson's description of the constraints that public sector agencies face. Regardless of what an agency's goal is and how clear it may be, problems in decision-making arise through the political constraints that are imposed on the agency's *process* in achieving its goal. For instance, a complex procurement system that restricts how equipment can be purchased or requiring public hearings before decisions are made needs to be taken into account by program managers when making decisions.[10] Furthermore, agencies also contend with "contextual goals", that is, other goals that "define the context within which the primary goals can be sought (p. 129)."[10] For example, public hospitals must ensure patient confidentiality in addition to their main goal of providing care.

Wilson argues that these constraints and contextual goals have several significant consequences on how managers make decisions, but I will discuss three main ones here. First, managers end up with an incentive to focus on the constraints and contextual goals their agency faces as opposed to the tasks it needs to accomplish.[10] The process becomes more important than the outcomes because managers need to satisfy other powerful interests that influence how the agency operates. Second, the variety of constraints on an agency increases the number of potential actors that will intervene in the agency's activities.[10] Each of those actors represents a constituency that the agency has to satisfy in some way, and, if those constituencies are many and/or varied, the agency loses decision-making power. Third, as the number of constraints and contextual goals increases, discretionary authority moves upward in the agency away from the front lines.[10] This occurs because administrators face greater risks in these situations and want to control the decisions being made.

Walt and Gilson built on these ideas further through their four element model of policy-making: content, process, actors and context.[11] They describe that decision-makers are constrained by their context at the governmental and institutional levels, by the process for decision-making which can be dynamic and transitional, and also by the content of the policy and the quality of the data used to develop it.[11] Decision-makers are also constrained by organizational forces that keep them from making full use of that information. Weiss and Bucuvalas argue that decision-makers are influenced and constrained by "procedural, structural and ideological (p.19)"[3] frameworks as well as by larger political influences. In addition, many of the constraints that guide administrators' work are defined externally through legal and budgetary decisions.

The last approach to decision-making to be discussed here is Cohen, March and Olsen's **"garbage can model"**. They describe an amorphous process where four relatively independent

streams come together for any given decision: problems, solutions, participants and choice opportunities.[12] The authors argue that these four streams exist concurrently and decisions emerge when an appropriate solution is identified for any given problem by existing participants at a time when a decision is expected. The garbage can model is a non-linear, non-rational approach because it argues that decision-making is not "a process for solving problems (p. 16)"[12] and choices are only made when the right combination of problem, solution and participants makes action possible.

The three approaches described here—incrementalism, constraints in bureaucracy and the garbage can model—outline decision-making as a political process that is influenced by many actors and interests outside the agencies and programs themselves. Managers are making decisions incrementally while facing constraints from many sources. Their process is not rational and oftentimes decision points only arise when the right combination of factors align. In essence, decision-makers are faced with the combined interest of applying the best evidence to address an ongoing issue and of reconciling competing forces in order to maintain the stability of the system as a whole[3], so the automatic uptake of data into programmatic and policy decision-making cannot be assumed. The political science literature suggests that this is not an aberration to be corrected but a predictable context for HIV/AIDS programs attempting to integrate surveillance data in their decision-making. By identifying the factors that define and influence the decision-making environment for HIV/AIDS programs, we can more clearly identify the forces that impede the use of data to guide local decisions. The subsequent step for program managers then becomes distinguishing which barriers are actionable, which can be leveraged to make data-driven decisions more likely, and which data can provide an avenue for managers to navigate the competing constituencies that shape programmatic choices. In the following section, I present an ideal cycle for surveillance data as well as a brief review of how data utilization has been described by other researchers in social science.

SURVEILLANCE DATA CYCLE

The ideal cycle for surveillance systems should include an additional step as a part of the process to complete the cycle of data utilization: data translation (see Figure 1).[*] In an idealized cycle for HIV/AIDS surveillance data, the data are gathered and used to set priorities by identifying populations and areas that should be targeted for intervention. Those priorities are translated into programs by identifying appropriate interventions that will reach the targeted populations and meet their needs. In order to reach those populations, resources are allocated and program activities are implemented based on priorities established earlier. The hope is that the programs have a positive effect, be it in preventing infections, disease or disease progression. The continuing data collection—for surveillance as well as for program and evaluation—helps reassess priorities and the cycle begins anew. Ensuring that the priorities are driven by data and that those priorities are translated into action is a key component in the process to ensure data utilization.

[*] A similar cycle for data utilization has been described previously within the field of nutrition as the Data-Action Cycle, but its applicability goes far beyond nutrition surveillance (see United Nations Administrative Committee on Coordination/Sub-Committee on Nutrition, 1989).

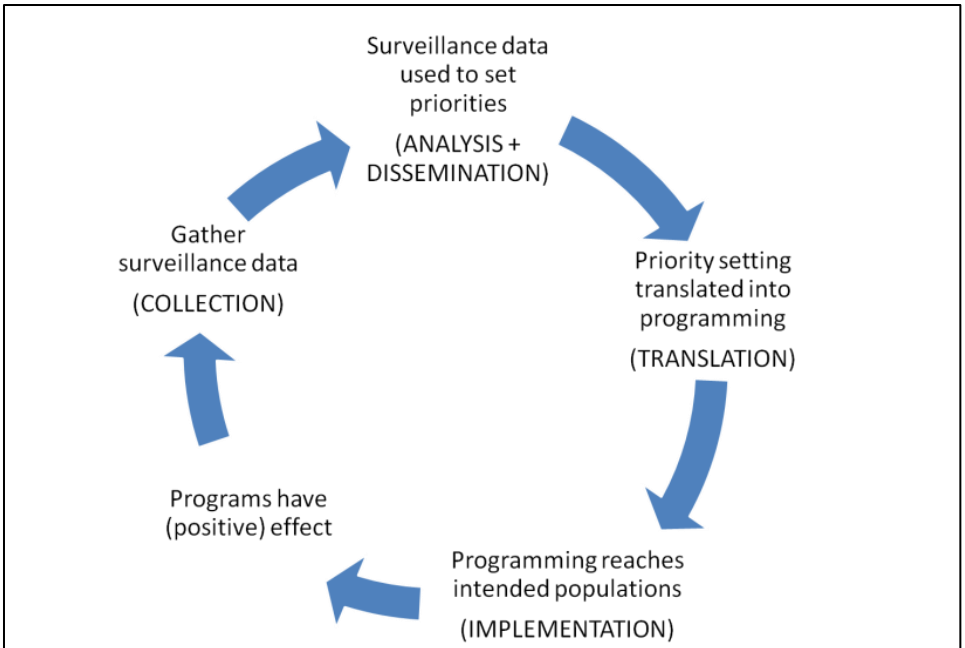

Figure 1. Ideal cycle for surveillance data utilization

While this cycle is a theoretical representation of how surveillance data utilization can or should work, it does not exist in a void from its surroundings. It is not linear but iterative. Once a well-synchronized surveillance system is working correctly, these steps are all happening concurrently. As such, there are a number of forces that are influencing this process—the movement from surveillance data to targeted programming—continuously. The whole cycle is functioning in a larger political environment that influences the program as a whole as well as its specific activities. Many factors influence this cycle because they influence how decisions are made at each step of the process, especially in relation to the programmatic/policy level.

Now I turn to how data utilization has been approached in social science. Attempts to operationalize the concept "use of research" resulted in the description of three types of use. These types broadly capture many of the functions that research and data can serve for decision-makers:

1. Instrumental/engineering: acting on research results in specific, direct ways,
2. Conceptual/enlightenment: using research results for general enlightenment; research influences actions indirectly,
3. Symbolic/legitimative: using research results to legitimate or sustain pre-existing positions around an issue.[13] †

In some of her early work, Carol Weiss identified seven models of research utilization. These models range from ones that can be described as "rational", such as the Knowledge-Driven Model, to others that are strictly one-dimensional, such as the Political Model.[14] These models can be correlated with the three types of use of research described earlier. The following table summarizes the models from Weiss' paper along with a type of use ascribed to it.

† For further discussion about types of research use, see [8] (Weiss and Bucuvalas 1980).

Table 1. Models of research utilization [14]		
Model	**Description**	**Use**
Knowledge-Driven Model	Assumes that knowledge's existence presses towards use. However, little knowledge is so compelling as to drive implementation. Cycle: Basic research → applied research → development → application	Instrumental Use
Problem-Solving Model	Application of research results to pending decisions. Expects that evidence will reduce uncertainty and solve a policy problem. Cycle: Definition of pending decision → identification of missing knowledge → acquisition of research → interpretation of results for decision context → policy choice	Instrumental Use
Interactive Model	Interactive search for knowledge and research is only a part of a complex process based on experience, politics, pressure, judgment.	Instrumental & Conceptual Use
Political Model	Research is used to support pre-existing positions around an issue or decision.	Symbolic Use
Tactical Model	What matters is not the content but the fact that research is being done around the issue.	Symbolic Use
Enlightenment Model	Concepts and theoretical perspectives resulting from research that permeate the policy-making process.	Conceptual Use

By describing these models, Weiss summarized the literature in research utilization and provided concrete frameworks that reflect the authentic circumstances for data utilization that are present in the policy-making world. I have linked them here with the types of research use in order to illustrate the role that data and research are playing in any given model. Are the data being used to bolster an existing opinion? Are they reducing uncertainty about a policy area? Are they informing relevant actors on new avenues for addressing a given problem? Identifying how one's data of interest can inform the policy-making process makes the likelihood of their use more likely.

For the question of surveillance data utilization in HIV/AIDS programs, the most relevant model is the Interactive Model because decisions are made regularly about the program's direction and activities. This model recognizes the iterative, complex interplay of research and data in the surveillance cycle. Weiss describes this model as "not one of linear order from research to decision but a disorderly set of interconnections and back-and-forthness that defies neat diagrams (p.428)"[14], which reflects the amorphous process that Cohen, March and Olsen espouse in their garbage can model. The Interactive Model also reflects other issues that Walt and Gilson[11] and Weiss and Bucuvalas[3] emphasize, such as political forces and the pressure they exert. It is this "disorderly" interplay of influences that must be identified and addressed as we study how surveillance data are used in local programs. The following section begins that exploration by categorizing factors that influence the decision-making process and in turn, their influence on the use of surveillance data.

FACTORS THAT INFLUENCE DECISION-MAKING

In order to develop a comprehensive view of the decision-making process, I synthesized the main influencing forces into three broad categories of factors: macro political issues, resources and data characteristics (see Figure 2). These represent the forces that influence the decision-making environment around program planning. This is a broad-based review of influencing factors with a few specifics drawn to the field of HIV/AIDS. Each of the categories contains a series of more detailed sub-categories that reflect the intricacy of each factor.

MACRO POLITICAL ISSUES

Within this category fall those issues that Walt and Gilson would refer to as "Context" and "Process".[11] These are the larger, systemic factors that affect every piece of the decision-making puzzle. These factors have been researched and addressed often in the literature but not always taken into consideration together (for examples see [2, 3, 11, 15-18]). Here macro political factors been grouped into five sub-categories: policy environment, organizational behavior, decision-making power, local capacity and communications.

Policy environment

The social, economic and political context that surrounds decisions made by government administrators is one fraught with challenges. Policy and program decisions have to be made, usually with limited time, in an environment with multiple viewpoints on any given issue and with multiple actors whose support may be necessary for success. This environment and the power that different actors wield can have a significant impact on how data are used for programmatic decisions and whether some information is weighed more than others.

Lindblom's argument in favor of incrementalism asserts that policy-makers have historical knowledge about policy changes that have occurred before, which gives them some basis for understanding probable consequences of future policy decisions.[1] In addition, their evaluation of limited changes ends up ignoring any policy alternatives that are politically unfeasible and thus irrelevant. That selection simplifies later analyses by concentrating on policies that may be viable. This combination of experiences and simplification provide a framework for successive policy choices that is actually practical in its execution.[1] The historical knowledge that decision-makers gain over time is an invaluable asset that allows them to evaluate pragmatically which potential alternatives have a chance of being selected and implemented, regardless of the data supporting one choice over another. In fact, later researchers have found evidence that administrators allow political pressures, cultural acceptability and their own experiences to dominate decision-making at the expense of evidence.[19, 20] Recent efforts by WHO in health guideline development have attempted to balance these tendencies by making values preferences clear in the guideline development process.[21] Since any given decision could have one consequence that is preferred over others, it is likely that different people would make different choices based on their local setting. Thus, the potential for preferences driven by values is acknowledged as an explicit part of the process and administrators are given the space to consider values in equal weight as costs or evidence of efficacy.[21]

Gilson and Raphaely present the most overarching description of the barriers that form part of the policy environment.[16] They argue that policy decisions are always contested—even if there is no decision at all—because there are always competing constituencies for any given issue. This is partially due to the different meanings that are attributed to policy alternatives by those who are interested in the outcome and these, in turn, are influenced by the policy

discussion. In other words, in addition to their analysis of the content of a decision, policy-makers need to take into account any constituencies vested in that decision as well as the process necessary to change the policy, if they want to make any headway.[16]

When considering the policy environment that surrounds the decision, administrators also need to take into account the laws that apply to the program's activities as well as funding agency guidelines and rules.[22‡] In sum, in order for prevention activities to be effective, planning must also incorporate information about the "political, legal, cultural, or social barriers (p.833)" to implementation of activities.[23] These barriers represent part of the constraints and contextual goals that program managers must satisfy through their decisions.

Organizational Behavior

How the organization itself functions can be one of the greatest challenges to an administrator trying to make decisions about a program's activities and targets. A review of the literature on diffusion of innovations identified that organizational learning can be impeded by the organization's own structures, processes and cultures.[24]

A study on strategic management in Sweden highlights two ways in which organizational behavior can influence the implementation process: through the formal structure and through the organizational culture.[25] The formal organizational structure is the relationship between tasks, individuals and formal and informal channels, and it affects implementation through its influence on the information, control and decision processes. The organizational culture—the cognitive and behavioral patterns that exist in organizations—works as organizational glue that affects the success of the implementation process.[10, 25]

Particularly in large institutions like health systems the process that governs how and which data are used to influence a decision may be determined far from the program itself. An organization's expectation of whether data will be used or not is often clear to those developing and implementing programs and policies even when that expectation is not made explicit. One way the organization can give weight to an expectation for data utilization is by providing support to its staff for that specific purpose. Further, the strength of that commitment can be evaluated by analyzing the kind and quantity of support that is provided. Organizations can pay lip service to data utilization in decision-making or they can provide time, resources and data sources for that utilization to take place.

Decision-Making Power

Decision-making power refers to the ability of individual program managers to make and carry out decisions regarding a program's direction. The decision-making power may be formal in nature, derived from the authority vested in a given office or position, or informal, derived from the ability manipulate and manage the politics surrounding a decision.

Decision-making power often resides in more than one individual but it is essential to identify the role that is played by HIV/AIDS program managers in the process. Organizational charts can show who *should* be making the decisions, but often times other actors influence the process significantly or gain control over it. The hardest situations to elucidate are those in which the influential actor is outside the organizational chart or even outside the organization itself.

‡ The barriers that the policy environment places on resources are discussed in the "Resources" section of this paper.

If there is any ambiguity around who holds the power to make decisions, to integrate data into priority-setting and to decide which populations get interventions and how, then it is quite difficult to direct resources and training to improve data utilization. In governmental agencies, decision makers at the federal, state and local levels may have completely different impressions about who is driving the process. Those differing impressions can lead to incorrect assumptions about how to intervene to improve programs and make them more reliant on data.

Those actors who are lower in the hierarchical scale of the organization and the decision-making process are often themselves more constrained in their decisions than those above them. Weiss and Bucuvalas found that local administrators saw themselves as less autonomous and more limited by organizational limits on possible courses of action.[3] Potentially due to these additional constraints their own decision-making, local administrators were more likely than their state and federal counterparts to feel that decision-makers ignore evidence that is inconsistent with their beliefs and set policy through political processes instead.[3] Similarly, Hutchinson and Johnston's study on research use among nurses found that nurses lacked the authority to change practice based on research results. This is partly due to the nurses' lower ranking within the organizational hierarchy below doctors.[26] All in all, the literature suggests that, regardless of high-ranking actors' attitude towards data utilization, low-ranking actors do not have the freedom to incorporate data and evidence into their work.

Local Capacity

When the adaptation and implementation of programs takes place in settings far removed from where the programs were developed, it is essential to assess the skills and technical capacity of the actors responsible for the program's implementation. In the specific setting of vertical HIV/AIDS programs, each locality can adapt any prevention strategies that are developed at the federal level to meet the needs of their epidemic profile. The skills necessary to identify priorities areas and plan prevention programs appropriately must be cultivated and maintained in administrators.

In order for program managers to better integrate data into their decisions, they must possess a basic understanding and appreciation for how to use and interpret data.[27] The obligation to identify any local capacity needs lies with the organization, and as such, it should foster and promote these skills if there is an expectation that data utilization will be an integral part of program planning.[28]

Heide *et al.* refer to the necessary skills and training to implement programs as "learning."[25] Within this concept they include both the knowledge needed to implement a new strategy as well as the process of determining and addressing any existing knowledge that might hinder the acquisition of new knowledge.[25] Others have also referred to the need for individuals to have abilities or skills necessary for data utilization and for converting evidence into prioritized strategies and programs.[22, 23, 29] In several practice-oriented contexts, decision-makers self-assessed their skills in critically appraising research and evidence as moderate and lacked confidence in those skills.[15, 26, 30] This suggests that local capacity is a key area that would benefit from additional interventions.

Communications

There are a range of issues that can be included under the umbrella term of "communication". Part of this category relates to the format in which data and research results

are presented and part of it lies in the channels that are available and used by the producers and users of data.[3]

Many studies have recognized that a barrier to data utilization lies in the format that is used to present and disseminate data. Managers, administrators and implementers are less likely to find and use data that are not presented in an understandable or compelling format, not action-oriented, available only in locations that are difficult to access and have a presentation style that is not user-friendly.[26, 27, 31, 32]

Also relevant to communications are the channels that are used to disseminate information. The information system of an organization encompasses all the possible mechanisms that play a role in the communications throughout the organization, both horizontally and vertically. In order to facilitate the implementation of a strategy, it needs to be promoted upwards, downwards and across the organization.[25] Establishing multiple, redundant systems for information dissemination increases the likelihood that important data reaches all of the intended users. In addition, well-connected individuals and their networks can be crucial in disseminating strategies.[24, 31] Several studies have identified concrete examples for improving dissemination with the intention to improve data utilization, such as meetings, conferences and other face-to-face approaches, trainings on data sources of particular value, providing research briefs via e-mail or through periodic printed reports, and using a website as a resource for consolidating relevant research results.[15, 30, 31, 33]

RESOURCES

The second category of factors that influences surveillance data utilization is resources. The availability of resources is a continual source of concern in the public health field, in particular when investing in prevention. It is widely acknowledged that there is a constant insufficiency of resources to meet the goals and objectives of almost all of the public health policies and programs that have been shown to be effective, efficacious or cost-effective worldwide. Nevertheless, it is important to identify "resources" as both a separate and distinct influence on the decision-making process as well as an indirect channel for organizational and/or political leadership to communicate their commitment to a program.

It should be expected that resource constraints can have serious, deleterious effects on the effectiveness of HIV/AIDS prevention programming. Resource constraints affect programs not only in the implementation stage by limiting the activities that are possible, but also in the planning stage by restricting the financial, human, technological and material resources that can be directed towards initiating new programs or improving existing ones.

It is a rare program that receives enough **financial resources** to meet all of its responsibilities. This is a particularly difficult concern in state and local agencies where funding for one program needs to cover multiple objectives, such as surveillance data collection and analysis and program implementation.[34] Financial resources for data processing and analysis must be appropriate to their value and utility. In addition, logistic connections between program and planning staff and data collection and analysis staff are critical in improving data utilization.[28]

The allocation of resources to a program, activity or strategy carries an implicit measure of its value to the organization, especially because financial resources have distinct consequences in the allocation of **human resources.**[25] Furthermore, in programs that are under-funded and undervalued, personnel turnover results in significant costs to the organization and program. Any investments in program staff are lost along with invaluable historical memory when

personnel leave a program. The continuity of data utilization in program planning, among other things, can become severely compromised when decision-makers leave their post. Personnel turnover can result from poor funding of staff positions or program activities, difficulties within the organization's bureaucracy but also from the lack of authority to make the decisions that superiors expect.[3, 33]

The **technological and material resources** that can improve program functioning have changed greatly in recent years. Computer hardware and software have become essential tools in healthcare provision and prevention activities. These tools (and the skills to use them properly) are extremely valuable for surveillance data collection, aggregation and analysis. With the appropriate resources, HIV/AIDS programs can take available data and analyze them to answer questions that are most relevant to them.[28] As for other material resources, access to transportation, basic equipment and supplies and even electrical power can be serious constraints in low- and middle-income country and rural settings.[35]

DATA CHARACTERISTICS

The last category of factors is data characteristics. Much of the literature related to barriers to data utilization and to recommendations for better integration of data into program planning makes a basic assumption that the data in question are appropriate, available and useful to decision-makers. This assumption is partially necessary in order to address issues concerning the relational and political factors that influence data utilization in decision-making. Nevertheless, any attempt to comprehensively identify the factors that influence data utilization in decision-making must also take into consideration characteristics that are specific to the data themselves.

Within this category topics include data collection and quality, data availability and accessibility, relevance of existing data to local administrators, and the data utilization process. While each of these sub-categories is reviewed individually, they are integrally connected and all contribute to having a successful source of information for program planning.

Data Collection

A surveillance system that collects biological and behavioral data on HIV/AIDS is usually developed in a centralized way. Even if data collection itself takes place in municipalities and states, the design of the system as well as the indicators of interest are often determined at a national level. Nevertheless, a key factor for influencing local decision-makers' use of data in their program planning is to collect data that are perceived as actionable.[22, 27] Particularly in communities where much of HIV programming is funded by outside and international donors, many administrators find themselves saddled with collecting data on indicators that provide information that only satisfies donor requirements and holds little programmatic value. A recent critique of funder-driven monitoring and evaluation indicators is worth noting as it questions the validity and predictive value of these indicators for program monitoring and comparison.[36] Given that resources are stretched to their limit, this critique also calls for a balance between monitoring needs and clinic capacity.[36]

Data Quality

The quality of the surveillance data being used to identify target populations and prioritize resources has great influence over the success of programs and activities. Users of data must have confidence that the data were produced by a system that reliably and accurately

captures the epidemiological picture in order to rely on the weight of the evidence before them.

Data quality encompasses a number of issues, including the validity and completeness of the data being recorded as well as the acceptability and representativeness of the system.[37] In order to be valid, the surveillance indicators need to accurately reflect the phenomenon they are trying to measure but also sufficiently sensitive to capture it. The completeness of surveillance data are also undermined by underreporting—not reporting of cases—and by lack of information and misclassification—blank responses or reporting cases incorrectly.[37] Completeness is also affected by the separate influence of acceptability, which is defined as "the willingness of persons and organization to participate in the surveillance system"[37] and this can apply both to those who are charged with reporting cases as well as patients themselves. If a disease, such as HIV/AIDS, carries with it a fair amount of stigma both patient and reporting entity may choose to not report the case, to report it late or to report it with misinformation. Lastly, data quality is also influenced by representativeness or how well the surveillance system captures the health event in the population and over time.[37]

Given these concepts, programs that rely on surveillance data to establish target populations and activities need to ensure that the data they are using are of the highest quality, are generalizable and are accurate. An additional step is recognizing the limitations of the local surveillance system and to attempt to make decisions on the best available data with acknowledgment to its weaknesses.

Data Availability and Accessibility

Once surveillance data indicators have been selected, the data have been collected and their quality has been ensured, the data need to reach the end users. Data availability and accessibility are two aspects of one concept: making existing data obtainable to those who are responsible for incorporating surveillance data into the program planning process.

Data availability concerns itself with asking what data exist that can be used for program planning:

- What data are available and from what sources?
- For those data that are available, are they disaggregated by municipality or state? Are only national data available?
- How do local staff know what data exist?
- How can local staff find out about what data are available to them?

Data accessibility centers around how users gain access to the data that are available to them:

- What data can be accessed at the local level?
- How do you access the data that you want, e.g. intra-organizational contact, published reports or research, reports within local program?
- What format is used to make the data available to users, e.g. online (public or intranet sites), using special software, mailed reports?
- Is that format accessible to most users?
- How often are data updated?

Part of this concept relates to using multiple communication channels to ensure that information that is central to the organization's mission or strategies is relayed to all relevant actors. A 2003 study of healthcare managers in Poland found that Ministry of Health officials believed that the Internet was the most effective channel for disseminating information while the

managers preferred printed materials available through the mail. Nevertheless and in spite of its own beliefs, the Ministry was not using its website as a source for appropriate and relevant services.[30] While the findings in this study may be less relevant in an increasingly digital age, it is important to highlight the split between the perceptions of the upper-level officials and managers in this study regarding dissemination of information, especially given the paucity of technological resources in developing countries.

Relevance at local level

The basis for the relevance of surveillance data to local level program staff is whether the data are pertinent to or connected with the program's planning, development, implementation and evaluation. When the data are perceived to be relevant to the program, they can be used to adapt broader strategies to local epidemic conditions. Much of the relevance of data to local decision-makers lies in the contributions that they have made throughout the process of designing the surveillance system.[27]

Data Utilization Process

How data are used is a key issue that needs to be addressed independently. Partly, this provides a secondary means of assessing how all of the other factors influence the data utilization process. This parallel assessment should identify the mechanisms by which local program staff utilize any data they have, whether good or bad, and use it to identify populations to target, allocate resources and so on. Part of evaluating those mechanisms requires including perceptions about the value placed on data utilization by program staff, and how staff are motivated, as individuals or by the organization, to use data.

Factors Working Together

Figure 2 is a graphical representation of the relationships and interactions that these three categories of factors have with each other and the decision itself. Macro political issues have direct influence on inputs to the decision, such as what data are collected and which ones are accessible, how relevant information gets distributed, how many resources are available and how they are invested. However, macro political issues also influence the decision itself by determining which decisions are acceptable as well as who should and who does make them.

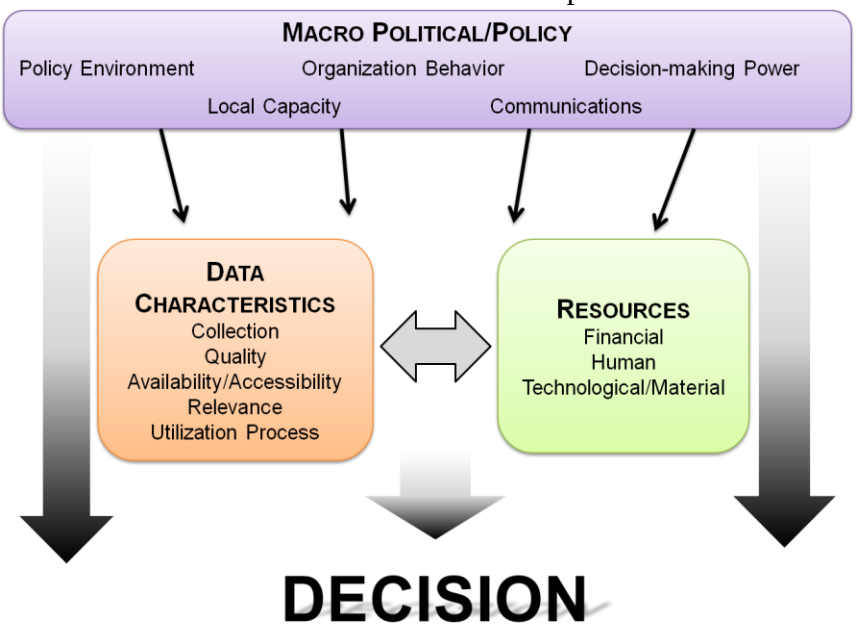

Figure 2. Factors influencing decision-making process

Resources and data characteristics constrain each other, as well as the decision itself, and influence each other's role in the planning process. Resources can affect how many data are collected and how well they are analyzed. Lack of resources also influences the extent of the program's activities. The best possible data sources can be used to target interventions, but they cannot increase the investments or the number of interventions.

Many factors in the decision-making model would be very difficult to change or influence. However, there are a few factors that are changeable and could be leveraged to facilitate overall data utilization. Once managers know the factors that are likely to act as barriers, they are in a better position to identify those which can be addressed. For instance, in terms of data characteristics, data collection can be improved by developing an exchange with local surveillance staff and program managers to ensure that the surveillance data being collected meet their needs for program planning. Evaluations of the surveillance systems' processes as well as periodic revisions of methods can help assure continuing data quality. These processes can be aided by identifying and then implementing multiple channels for data and research dissemination. Lastly, agencies could establish incentives and training programs to reduce personnel turnover and improve local capacity for program management, data analysis and rational data utilization.

DECISION-MAKING FACTORS' INFLUENCE ON SURVEILLANCE DATA UTILIZATION

Bringing together the factors that influence decision-making in a political environment with the surveillance data cycle presents a complex perspective on how to transition towards more data-driven programs. These factors have independent effects on data utilization and their influence points vary (see Figure 3).

Macro political factors exert a pervasive influence on every step of the surveillance data utilization cycle. These factors are experienced as pressures for policies, programs and activities to move in one direction over another, independent of any evidence to the contrary. The politics of HIV/AIDS influence what data are collected, how priorities are set, whether priorities become programming and whether program activities have sufficient coverage and intensity to have an impact at the local level. These pressures are experienced directly and

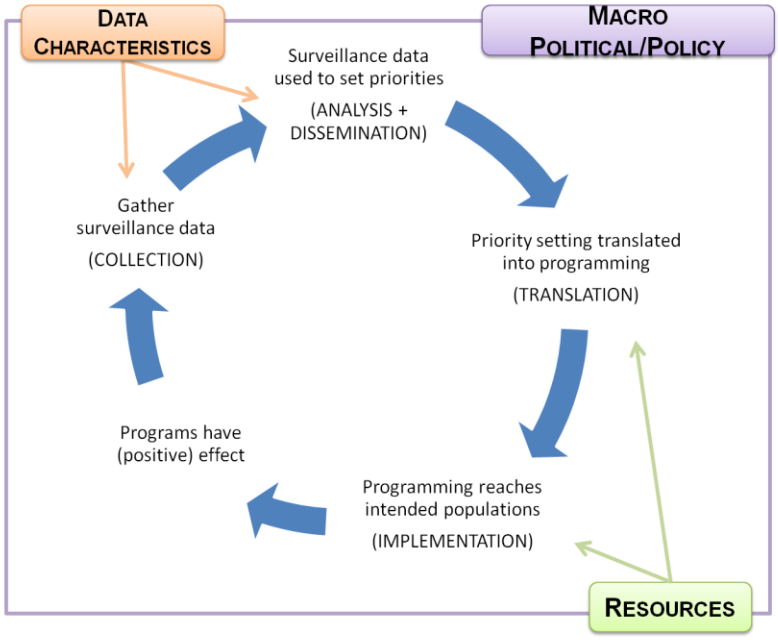

Figure 3. Decision-making factors influence the surveillance data utilization cycle

indirectly through resource allocation. In general, topic areas that are well-regarded, en vogue or the pet cause of someone in a leadership position often benefit from resources being sent in their direction, even if the epidemiological data do not support it. To some degree, HIV/AIDS benefits from this particular paradox. Even though HIV is ravaging many parts of the world, the funding directed towards it can be disproportionate with the burden of disease it represents in the local population or just disproportionate relative to other diseases, such as malaria or malnutrition.

Resources exert their influence mostly on two steps of the data utilization cycle: when decision-makers are translating their priorities into programming and when programs are being implemented. Managers and staff need access to data and research as well as the appropriate skill sets to help them develop responsive programs. These are based on numbers and skills of staff, capacity building, infrastructure and materials. Ensuring that program activities can reach the right target populations at the right time in the right setting requires money, people and support. Though resources are always lacking, especially in government-funded efforts, commitment to a program and its effectiveness is felt most through the resources that are allocated to it.

Data characteristics are felt most acutely in the data gathering and priority-setting phases of the surveillance data cycle. The quality and comprehensiveness of these steps are determined by the data themselves. Having a supportive macro political climate and adequate resources are meaningless if the data are substandard, unreliable or inaccessible.

CONCLUSION

In this paper, I have imposed a more reality-driven model of decision-making on an idealized cycle for surveillance data. The political nature of decision-making creates an environment with many opportunities for surveillance data utilization to be derailed. The scientific community –researchers, epidemiologists, content-area experts—has a responsibility to facilitate and advocate for data usage. To facilitate data usage we need to distinguish data translation as a currently missing link in the surveillance data cycle. Generating data, analyzing them and making them public are not enough if we want programs to be data-driven. If we want data to be integrated into in the decision-making processes for priority-setting and program development, then translation has to be incorporated into the cycle so that we can actively focus on it as well.

Once translation is recognized as an important piece, however, one must come to appreciate how complex the decision processes within translation are. Carol Weiss' Interactive Model for research utilization describes how the interface between invested actors can help identify the range of experiences and options in a given policy area.[14] Thus, even when data and research cannot provide a direct answer to a policy question, these types of information can get decision-makers closer to reaching potential policy alternatives.

Building on Weiss' Interactive Model[14], this paper shows how data utilization in any programmatic area necessarily takes place within a decision-making environment that is fairly political in nature. Instead of straining against that context, we should acknowledge the barriers that it presents and identify the leverage points that can facilitate data utilization. Those leverage points arise from a complete assessment of the factors that influence decision-making and the development of a comprehensive picture of the existing environment and its readiness for data utilization. An important consideration for political settings, though, is that in order for reliable

data to be used in guiding decisions, actors that are willing to take risks and advocate on behalf of data-driven decisions are crucial.

Although this complex view is applicable to other public health issues, HIV/AIDS is an illustrative case for understanding surveillance data utilization. In many settings the stigma associated with HIV/AIDS makes it politically unpopular to destine resources for the populations most at-risk for infection, regardless of what the data say. More importantly, the organizational, political and cultural factors that influence whether data are used in decision-making are much more common, subtle and difficult to pinpoint. Any opportunities to use surveillance data to direct programmatic efforts can be frustrated by those forces. Further, the expanding commitments to universal access to treatment for HIV/AIDS have resulted, in many countries, in the transition of this disease into a chronic condition. Providing universal treatment for HIV/AIDS necessitates a considerable financial commitment that is often undertaken at the expense of investments in prevention. One way to improve prevention activities—and subsequently reduce future cases of HIV—is by using the surveillance data at our disposal to identify and target areas and populations that are at the highest risk for infection. HIV/AIDS is a preventable condition that requires substantial and long-term investments in both treatment and prevention. Surveillance data can play an important role in targeting efforts by guiding local decisions in this complex political environment.

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CHAPTER 2: BARRIERS AND FACILITATORS TO DATA UTILIZATION IN MEXICAN HIV/AIDS PROGRAMS

Mexico is an ethnically heterogeneous middle-income country (MIC) with a population of 112 million.[38] Like other developing countries, Mexico now finds itself dealing with the dual burden of infectious diseases and chronic illness due to an extended epidemiological transition.[39] It is also is facing a mounting HIV/AIDS epidemic that is consuming a considerable share of healthcare expenditures.

Mexico's efforts to combat the HIV/AIDS epidemic have been multi-faceted, consistent and ongoing since the early 1980s. Much of the data necessary to focus prevention efforts and, consequently avert future infections, are already available in Mexico. Local, state-based HIV/AIDS programs are charged with addressing treatment and prevention needs simultaneously. Ideally, program activities, especially around prevention, are driven by surveillance data in order to ensure the best allocation of resources. Given similar resources and surveillance data, utilization varies by state, and underuse of these data can undermine the performance of prevention programs. In order to improve the impact of HIV/AIDS programs, it is essential to identify and understand the barriers and facilitators to surveillance data utilization as priorities are set in prevention programs at the local level.

Most studies that have explored the utilization of data and research results have focused on one of three likely factors influencing the utilization process: larger political influences, resource constraints and, occasionally, the data themselves (for a more comprehensive exploration of this topic, see [40]). Given the nature of HIV/AIDS, we might expect barriers to the use of surveillance data to take the form of political pressure on state programs not to target stigmatized groups in any visible way, but there are also a host of more subtle barriers to the use of data that arise in reviewing state level implementation in Mexico. In order to address both overt and subtle influences, this study explores concurrently all three categories of factors that program administrators face in four states in Mexico. Political, resource and data factors each represent a different influence point on data utilization. Thus, to get a clearer picture of how managers make programmatic decisions and the role of data in that process, we must consider these factors simultaneously. The value of considering all three areas together is that it allows for an exploration of the issues that confront administrators in a way that reflects their experiences more realistically. Taking any one part out of the system means leaving some potential explanatory power out of consideration. If we are to move beyond a rationalistic approach for describing decision-making and the use of data in that process, then we need to study how decisions are made in a more holistic manner. By taking this approach, this paper provides a more complex insight into the factors that influence how program managers use data when they make decisions.

It is important to note that this study is focusing on one part of decision making for HIV programs that is potentially data-driven. Effective programs in HIV/AIDS prevention are based on appropriate targeting of activities *and* selecting suitable interventions. This research does not encompass both of those subjects. The focus here is on the use of surveillance data to target activities appropriately. The selection of effective interventions that meet the needs of the local epidemic profile should also be based on data and research. In addition, selected interventions

should be adapted to match the local context. However, this portion of HIV/AIDS programming is beyond the scope of this work but should be considered in future research.

For this paper I will begin by reviewing the Mexican health system and its response to HIV/AIDS. Following a review of the methods, the results section will outline the barriers and facilitators to data utilization under each category of factors with illustrative quotations garnered during the study. The latter parts of the paper will discuss the implications of these barriers and facilitators as well as discuss how these issues can be influenced to improve data utilization.

BACKGROUND

This section provides an overview of the Mexican health system and is followed by a description of the Mexican HIV/AIDS epidemic and the steps that have been taken to address it, including the surveillance systems that have been implemented thus far. This section will highlight the intricacies that public officials must navigate in order to incorporate surveillance data in their local HIV/AIDS programs.

HEALTH SYSTEM DEVELOPMENT AND STRUCTURE

The Mexican constitution of 1917 introduced the concept of healthcare for the working class as part of a package of social security services, which were later expanded to cover all Mexicans. The foundation of the modern health system began in 1943 with the creation of the Ministry of Health (*Secretaría de Salud, SSA*) and the Mexican Institute for Social Security (*Instituto Mexicano del Seguro Social, IMSS*). In 1959, the Institute for Social Security and Services for Civil Servants (*Instituto de Seguridad y Servicios Sociales de los Trabajadores del Estado, ISSSTE*) was established to serve public-sector employees and their families.[41]

A series of reforms have taken place since the late 1970s aimed at decentralizing the system.[41, 42] In 1999, *SSA* completed its decentralization process and transferred human, material and financial resources and responsibilities from the federal level to the states. This allowed states to have broader authority in hiring personnel and controlling the provision of health services. In addition, state budget participation increased from 59.0% in 1996 to 73.7% in 2000.[43] In the 1990s and early 2000s the system was reorganized, and *SSA* took on the primary role of coordinating, monitoring and regulating the system and currently is the steering agency for the health system.[41-43] Through this decentralization process, the federal government has retained the authority regarding policies, but the programmatic decision-making power is vested in state authorities. For instance, the federal level determines which interventions are covered in an essential package of basic services. States are responsible for conducting the actual healthcare delivery of those interventions through their local clinics and facilities.

Matching the trend in most countries, total health expenditure as a percentage of GDP has been rising. In 2000, prior to healthcare reform, it was estimated that Mexico spent only 5.6% of GDP on overall health spending, well below the Latin American average of about 7%.[41] Since then, healthcare spending rose to 6.5% in 2006.[41] During that time the government's portion of spending on health as a percentage of total health expenditures also grew. By 2006 *SSA*'s budget increased 69% in real terms.[41]

The social security institutions covered approximately 56.4 million workers in 2005. *IMSS* is the largest insurer covering about 79% of the population insured through the social security system. This is followed by *ISSSTE* covering about 19%. Informal workers, the rural uninsured and the unemployed accounted for about 45 million people in 2005 and received their care through *SSA* (see Table 1).[44] Only about 4% of the population receives its care through the

private sector. Each health system has its own financing mechanisms, service delivery structure and network of clinics and hospitals.[42]. These three systems, described in more detail below, serve the majority of patients receiving antiretroviral therapy (ART) in Mexico.

SSA provides services for the uninsured through a very decentralized system and services are primarily managed at the state level through State Secretariats of Health (*Secretarías Estatales de Salud, SESA*) with financing from federal and state sources as well as fees for services.[43, 45] *SSA*'s structure allows states to have autonomy in general health care services, but HIV/AIDS care and antiretroviral planning and procurement is managed at the central level. The National Center for Prevention and Control of HIV/AIDS (*CENSIDA*) monitors patient care, forecasts need for antiretroviral drugs, and coordinates the volume of antiretrovirals to be purchased. The cost of antiretroviral drugs in *SSA* is covered by the Fund for Protection Against Catastrophic Expenditures, and antiretroviral expenditures are not capped.[46] The HIV/AIDS programs at the state level manage both treatment and prevention activities but for different target populations. State programs manage treatment regimens and coverage through overview of the local health facilities that treat people living with HIV/AIDS (PLWHA) that are *SSA* beneficiaries. However, for prevention, state programs conduct activities with any at-risk population in the state regardless of health system affiliation.

Table 1. Coverage of by healthcare provider of total population and persons living with HIV/AIDS receiving ART

Healthcare Provider	Beneficiaries	Coverage of Total Population*	% of PLWHA covered by each plan
IMSS	Formal sector workers	43.9% (~44 million)	40%
ISSSTE	Public sector workers (federal and state employees)	10.6% (~10 million)	7%
SSA	Informal workers, rural uninsured, and unemployed	44.4% (~45 million)	51%
Other Government-based Providers**	Government workers not covered by *ISSSTE*	1% (~1 million)	2%
Private sector	Individuals paying fees charged per service	4%	Unknown

* This category sums up to over 100% because many persons that are eligible for social security-based care also seek care from the private sector.
** This is a small category that includes the service systems for Mexican Petroleum Workers (PEMEX), the armed forces (SEDENA), the Navy and other insurance plans for government workers.

Source: Adapted from Frenk, et al., 2003 and PAHO, 2007.

ISSSTE provides services to public sector employees, retirees and their families through a decentralized structure, similar to *SSA*'s, which allows for some autonomy at the state level.

However, HIV/AIDS care as well as antiretroviral planning and procurement is coordinated centrally through *ISSSTE's* federal-level Department of HIV/AIDS and Sexually Transmitted Infections (STIs).[46] In terms of prevention, *ISSSTE* facilities at the primary level are expected to incorporate HIV prevention messaging and activities into their ongoing prevention activities for beneficiaries. Additional prevention activities at secondary and tertiary level facilities in *ISSSTE* are often at the discretion of the treating physicians.

IMSS serves private sector employees retirees and their families. *IMSS* operates through a decentralized structure that is similar to *ISSSTE*; the difference is that local autonomy exists at the regional level known as the *delegación*. Each *delegación* consists of one or more states (or jurisdictions in the case of Mexico City). In *IMSS*, HIV/AIDS care, as well as antiretroviral planning and procurement, is decentralized.[46] *IMSS* has a similar system for HIV prevention as *ISSSTE* does: deliver HIV-specific messaging through existing prevention channels. Not surprisingly, HIV prevention messaging at these institutions is insufficient and not well targeted since it competes for funding and attention with many other health issues and the message are directed at the beneficiary population as a whole.

The private sector provides fragmented services to individuals that are based on fees charged per service. While it is estimated that 4% of Mexicans receive some or all of their care through the private sector, it is unknown how many PLWHA access treatment and care services privately.[43]

In the following section, I describe Mexico's response to HIV/AIDS, including a review of the epidemiology, surveillance system, prevention and treatment efforts as well as government financing.

HIV/AIDS IN MEXICO

The first case of AIDS was diagnosed in Mexico in 1983. The growth of the epidemic was slow at first and then grew exponentially from the mid-1980s until the early 1990s. By June 2010, Mexico reported 141,356 cumulative cases of AIDS with approximately 220,000 HIV infections.[4] The population prevalence in Mexico is 0.3% making it a concentrated epidemic with several high-risk groups with an HIV prevalence of 5% or higher.[47, 48]

AIDS has primarily affected 15-44 year-olds of both genders, who account for 77% of cumulative cases.[4] The primary mode of transmission is known for 67% of reported AIDS cases, with sexual transmission accounting for 96% of cumulative cases.[4] It is estimated that 82% of HIV infections occur in men and 18% in women.[4] The HIV/AIDS epidemic in Mexico remains concentrated in marginalized populations. Prevalence among men who have sex with men (MSM) is estimated at 23%, injecting drug users (IDUs) at 6% and female sex workers (FSWs) at 2%.[47] Migrants are also considered an at-risk population. By 2000, about 12.7% of cumulative AIDS cases in Mexico occurred in persons who had previously lived in the U.S., with an even higher proportion of cumulative cases (14%) among those who were originally from small towns in Mexico.[49, 50]

In response to the burgeoning epidemic of HIV/AIDS in Mexico and around the world, the National Committee for AIDS Prevention was created in February 1986 to evaluate the epidemiologic situation in Mexico, create guidelines for diagnosis, treatment, prevention and control, and coordinate implementation of the established guidelines. In 1988, the Committee was transformed into the National Council for the Prevention of AIDS (*Consejo Nacional para la Prevención del SIDA, CONASIDA*) in order to formulate and disseminate policies and strategies regarding HIV/AIDS and to establish specific resources for its work.[51, 52] Also in 1988

State Councils were established in order to replicate this model locally.[51] In 2001, *CENSIDA* was created, and it has assumed *CONASIDA*'s functions of setting norms and monitoring the epidemic.[52]

HIV/AIDS Surveillance in Mexico

The response to HIV/AIDS in Mexico has included a wide-spread effort to establish effective biological and behavioral surveillance systems (see Table 2). The outset of the epidemic was characterized by data collection on the distribution and frequency of cases. In 1983 the National Registry of AIDS Cases was started and is currently maintained by the General Epidemiology Directorate (*Dirección General de Epidemiología*, *DGE*).[53] Biological studies as well as behavioral surveys have been conducted on an ongoing basis since the late 1980s.

Biological studies were initiated in 1985 and were later followed by sentinel surveillance surveys. Between 1987 and 1991, HIV serological studies were conducted among paid and voluntary blood donors which helped identify this group as one at very high risk for infection and eventually prompted legislation prohibiting paid donations and establishing mandatory screening of all blood products.[54]

Table 2. Timeline of collection of HIV/AIDS surveillance data in Mexico.

1983	Diagnosis of first AIDS cases in Mexico.
1985	First serological studies in MSM. Beginning of testing at blood banks.
1986	Legislation is passed to make AIDS a reportable disease.
1987	National Registry of AIDS Cases is created. Sale of blood and blood products prohibited by law. First national seroprevalence study conducted.
1988-91	Initiate sentinel surveillance in high-risk sub-populations. Serological studies in paid and volunteer blood donors.
1987 and 1988	Knowledge, attitude and practice survey series in general population over 15 years of age.
1990	*DGE* prints first HIV/AIDS surveillance manual. Manual revised in 1998.
1995	Responsibility for sentinel surveillance goes from the *DGE* to *CONASIDA*.
1998	*SSA* establishes new mortality surveillance system.
2000-2005	Ongoing surveys about sexual behavior among high-risk populations.

Source: Adapted from Dirección General de Epidemiología, 1998, Magis-Rodríguez, et al., 2008 and Noriega-Minichello, et al., 2002.

Mexican authorities initiated behavioral surveillance in 1985 by conducting questionnaires with homosexual and bisexual men in Mexico City.[54] Beginning in 1988, sentinel surveillance was conducted and demographic and behavioral data were collected from MSM, FSWs, prisoners and hemophiliacs in eight cities in Mexico.[48] The system was later formalized

in 1990 within the surveillance guidelines. Currently, sentinel surveillance is conducted by *CENSIDA* among pregnant women, FSWs and IDU. Demographic information is collected along with information on behaviors such as sexual practices, frequency of condom use and engagement in high-risk behaviors.[54] Behavioral surveys in at-risk populations have continued to be implemented by *CENSIDA* and non-governmental organizations (NGOs) to monitor trends in sexual behaviors among in MSM, IDUs, and male and female sex workers.[55]

Mexico has been following HIV/AIDS through surveillance from the earliest days of the epidemic and benefits from such an early response. There are substantial historical data on case numbers and continuing efforts to address underreporting and missed cases have made the system more robust. However, for both biological and behavioral data there are drawbacks. Biological data, such as reporting a case of AIDS, are collected at municipal levels and data are aggregated at *DGE*. Biological data are available broken down by state but cannot be disaggregated further, which complicates local level decision-making. In addition, HIV testing at tuberculosis clinics is limited at best.

As for behavioral information, there is no systematic system for data collection. There are little to no data collected on a national basis and most recent data have been generated through surveys, which are conducted on a semi-regular basis. Thus, while behavioral data reflect trends in at-risk populations, it is not clear whether they reflect variations across the country. A specific example is the case of migrants. Several states in Mexico include migrants as a vulnerable risk group, but most behavioral studies are focused on other risk groups, such as MSM and sex workers. However, it should be noted that efforts have been made to add sexual risk behavior questions to national health surveys.

Prevention and Treatment Efforts

As shown earlier, the Mexican health system is fairly complex in its provisions of services. Treatment and care are offered through large health institutions that each have their own hospital networks, funding streams and systems for forecasting. However, general prevention services for HIV/AIDS are organized and provided through *SSA* at the federal and state level.

SSA, in its role as coordinator and regulator of the health system, sets the strategies for HIV response efforts. The strategy for prevention activities that is set by *CENSIDA* at the federal level is dispersed to the states for implementation. However, estimates suggest that prevention programs are not reaching the most at-risk populations. A 2007 report from UNAIDS indicates that about 55% of male sex workers, 28% of FSW and 18% of MSM were reached by HIV prevention activities, while only 5% of IDU—male and female—were reached.[56] Low coverage of prevention programs may be due to social and cultural taboos that pressure programs to limit their work with these populations.

In terms of treatment, Mexico began providing ART for persons living with AIDS in 1993; however by 1997 only two of the major health institutions, *IMSS* and *ISSSTE*, provided the treatment, accounting for 54% of patients nationwide. In 1998, *SSA* began providing ART to pregnant women and uninsured persons less than 18 years of age.[55, 57]

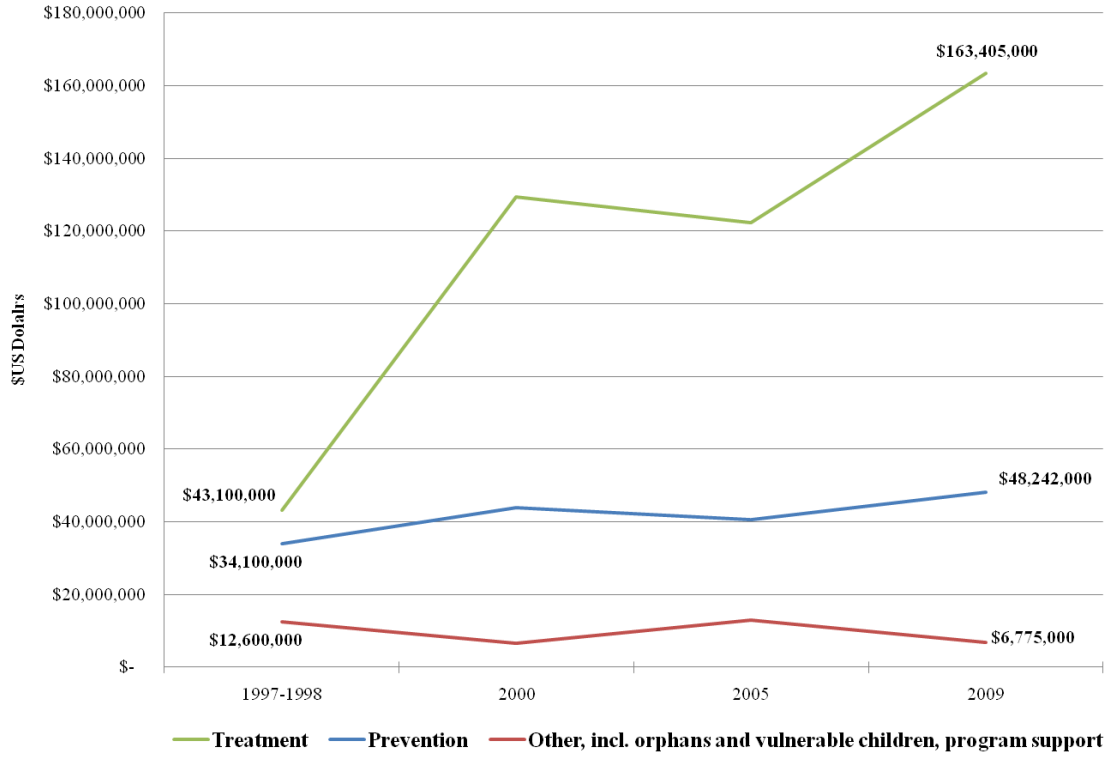
In August 2003, *SSA* made a commitment to provide free ART to all persons with HIV/AIDS. Through *Seguro Popular*, a safety net program for the uninsured managed by *SSA*, any uninsured person in need of ART is eligible for immediate enrollment.[39] By 2009 it was

estimated that about 71% of eligible PLWHAs were receiving treatment.[58, 59§] Of those PLWHAs receiving ART, about 98% are served by *SSA*, *ISSSTE* and *IMSS* (see Table 1). The remaining 2% of patients receive treatment through private health clinics or health systems such as Petroleum Employee Benefits, Armed Forces Benefits or through the private sector.[55]

Financing HIV/AIDS Efforts in Mexico

Trends in spending for HIV/AIDS in Mexico have transitioned from prevention to treatment with the advent of ART regimens and the guarantee for universal access to ART. Starting in the mid-1990s, overall spending on HIV/AIDS increased but that rise in spending has been directed almost entirely towards treatment and care activities. Between 1998 and 2000 prevention spending dropped from 38% to 24.4%, while spending on treatment rose from 48% to 72%.[52] This trend has continued through 2009, with treatment accounting for 75% of overall spending on HIV/AIDS and prevention accounting for 22% (see Figures 1 and 2).[59] The spending in the "Other" category has shifted over time from larger expenditures around blood banks and treatment of STIs to smaller ones for program support and services for orphans and vulnerable children.[59, 60]

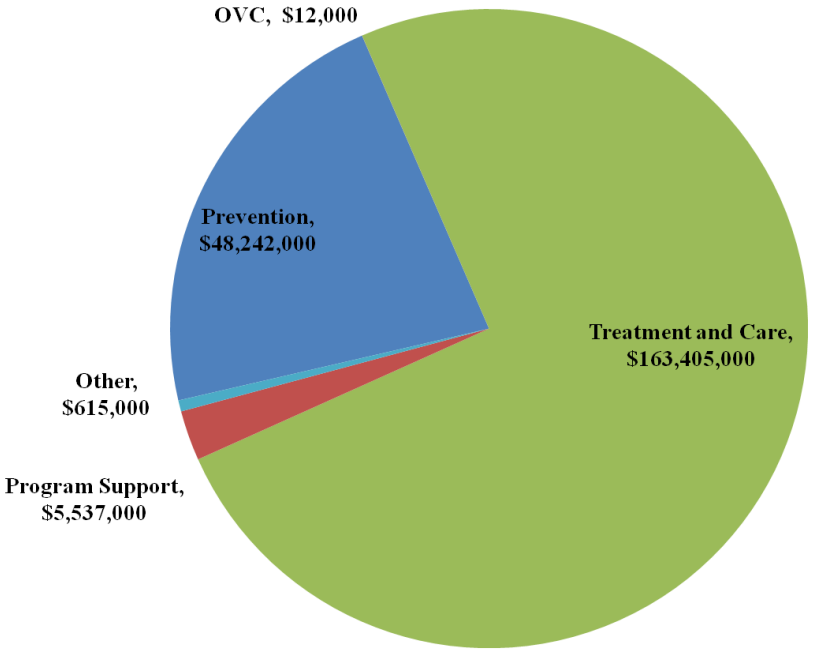
Figure 1. Historical Spending on HIV/AIDS in Mexico, by category, 1997-2009



Adapted from J.P. Gutiérrez, et al., 2004 and UNAIDS, 2010. Amounts are in USD.

§ This estimate was reached under WHO's 2006 ART guidelines. Under 2010 guidelines, which recommend starting ART earlier at 350 CD4 or less, Mexico's ART coverage rate drops to 54%.

Figure 2. Total Expenditure on HIV/AIDS in Mexico by Category, 2009



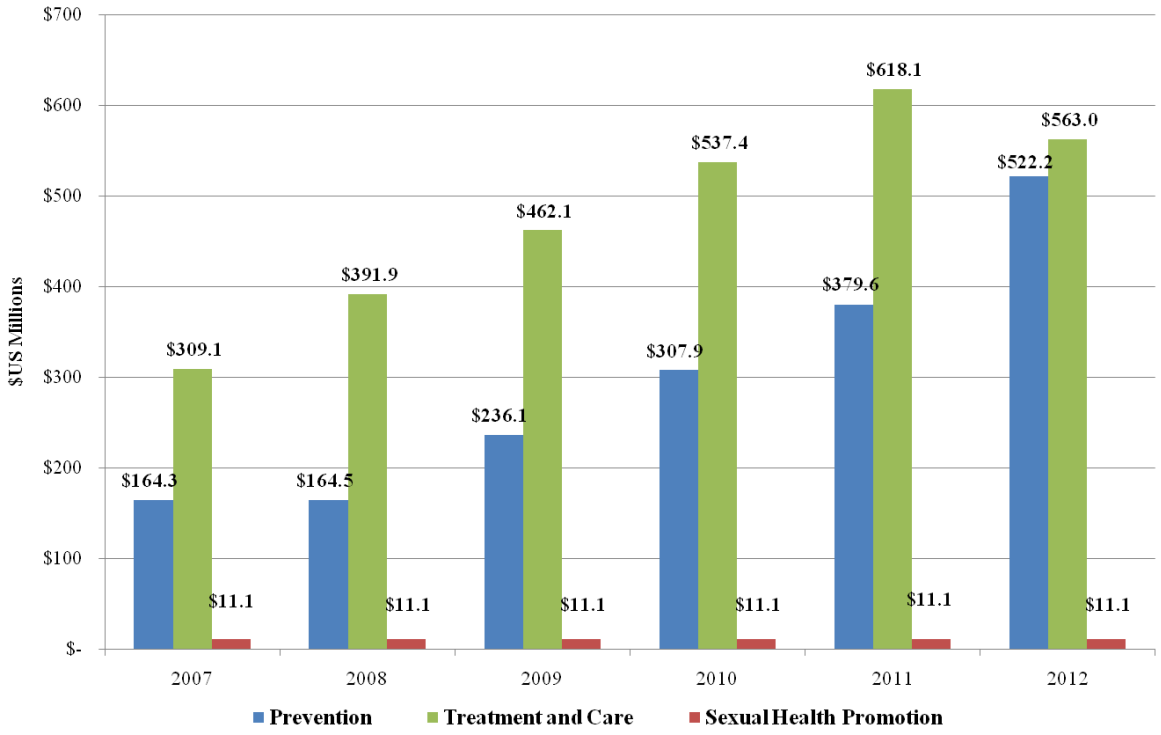
Source: Adapted from UNAIDS 2010. Amounts are in USD.

In 2009 it was estimated that Mexico spent over US$218 million on HIV/AIDS, and more than 99% of that funding was provided by the Mexican government.[59] The 22% of funding directed towards prevention was destined for activities including social communication, voluntary counseling and testing, social marketing of condoms, programs for at-risk populations and prevention of mother-to-child transmission. An additional 3% was directed towards the planning, management, monitoring and evaluation of the program. Small amounts of funding were also invested in programs for orphans and vulnerable children.[56, 59]

Compared to similar MICs that have concentrated HIV epidemics, Mexico is making substantial investments. With the exception of Brazil, Mexico is spending more on HIV than any other country in Latin America.[59] In terms of the proportion of spending on treatment and care, Mexico is comparable to Chile, Argentina and Brazil.[59]

The National Response Program for HIV/AIDS projects increasing expenditures on HIV/AIDS over the course of the current six year administration (see Figure 3).[47] Between 2007 and 2012, total expenditures on HIV/AIDS are projected to reach $1,096 million. The majority of the spending is projected for treatment and care followed by prevention. For 2012, it is assumed that a goal of the Action Plan to reduce the costs of ART by 30% will have been met thus lowering the necessary funding for treatment. Sexual health promotion spending is held constant over the period in question.[47]

Figure 3. Expected Spending for National Response Program for HIV/AIDS and STIs, 2007 - 2012



NOTE: Expenditures presented here were re-calculated from original amounts in Mexican pesos based on the average exchange rate from 2007 (US$1/10.8 Mexican pesos).
Source: Adapted from Córdova Villalobos, et al., 2008.

WHY HIV/AIDS? WHY MEXICO?

HIV/AIDS in Mexico presents an ideal combination to study data utilization because it represents an illustrative example of several key issues. First, due to the stigma associated with HIV/AIDS and the populations who are most at risk for becoming infected, it is often politically unpopular to develop and implement prevention and treatment strategies that are directed to persons considered to be socially objectionable, such as homosexual men or sex workers.[61] In Mexico as in many other countries, it is often the case that political and cultural forces frustrate opportunities to use surveillance data to direct programmatic efforts.

Further, the expanding commitments to universal access to treatment for HIV/AIDS have resulted, in many countries, in the transition of this disease into a chronic condition. Universal and continuing treatment for HIV/AIDS signifies a considerable financial commitment that is often undertaken at the expense of investments in primary prevention. One way to improve prevention activities—and subsequently reduce future cases of AIDS—is by using the surveillance data at our disposal to identify and target areas and populations which are at the highest risk for infection. HIV/AIDS represents a preventable condition that requires substantial and long-term investments in both treatment and prevention where surveillance data can play an important role in targeting efforts.

Second, it is especially important to describe the data utilization process in MICs and those with concentrated HIV epidemics like Mexico. MICs are generally politically stable with a

functioning health infrastructure in place, even if it is limited. Mexico, like many other countries, has undergone decentralization of its health sector resulting in differing perspectives and goals between the central and local levels. In many MICs, HIV/AIDS services for treatment, care and prevention are delivered through government-based or government-affiliated institutions. This type of healthcare delivery system, and the greater economic base of MICs, forces countries to spend their own resources combating HIV even while they are not receiving any outside aid to bolster their efforts. Although this situation forces a greater amount of responsibility on MICs to address both treatment and prevention for HIV, it also allows a greater freedom in decision-making because they do not have additional donor preferences to take into account.[**] In other words, MICs have more discretion in their programmatic decisions because their programs are essentially self-funded. A potential disadvantage of greater discretion is that it can also lead to limits in funding and political, social and cultural limits on the range of activities that programs are permitted to implement.

In addition to these considerations, Mexico provides several advantages for this project. First, Mexico's federated political system has two important characteristics worth considering. Central influence comes to bear on local decision-making, which is an important feature to include in this research because it allows the characterization of outside influences on local programmatic decisions. On the other hand, the shared political and financial structure between the four programs in this study will remove some of the variability among programs at the local level. Even as program infrastructure and funding vary at the state level due to local political considerations, the programs' placement within the larger health infrastructure provides a baseline of similarity between them.

Finally, unlike countries with early and comprehensive prevention programs for HIV/AIDS, Mexico represents a more realistic case. The country has enough resources to invest in HIV prevention as well as the health infrastructure to collect the data necessary to guide those efforts.

METHODS

STUDY SITES AND PARTICIPANTS

Four study sites were selected for this study to represent the variety of state HIV/AIDS programs in Mexico: Jalisco, Mexico, Mexico City and Sonora. A comparison of state characteristics is shown in Table 3.

Sixteen individuals participated in this study. Participants were selected using purposive sampling on the basis of their relationship with the HIV/AIDS programs at the states included in the study. Participants were drawn from the local state programs, *SESA*, *IMSS* and *ISSSTE*. These participants were selected for their experience and knowledge regarding HIV/AIDS surveillance data and the state HIV/AIDS programs. Participants included persons working at the programmatic level in surveillance data collection, analysis or use, program planning, program management and resource allocation. Any staff member holding a position with one of these job responsibilities was asked to participate. Although participants include *IMSS* and

[**] This may change soon since Mexico was recently awarded a grant through the Global Fund for AIDS, TB and Malaria that will be directed towards HIV prevention efforts in vulnerable groups. This grant begins implementation in 2011.

ISSSTE viewpoints, this study is focusing on the experience with prevention at the state programs that are part of *SSA* because their mandate demands broad-based coverage.

Table 3. Study site comparison

	Population, 2005[a]	% Urban / % Rural[b]	Political party currently in power *	# of AIDS cases, cumulative[c]	Most At-risk Populations (MARPS) **
Jalisco	6,752,113	86% / 14%	PAN	10,965	CSW, MSM, "Gay", Indigenous
Edo. Mexico	14,007,495	87% / 13%	PRI	15,718	CSW, MSM, Migrants, Indigenous
Mexico, DF	8,720,916	99.7% / 0.03%	PRD	22,984	CSW, MSM, "Gay"
Sonora	2,394,861	86% / 14%	PAN	2,355	CSW, IDU

* PAN: Partido Acción Nacional, PRI: Partido Revolucionario Institucional, PRD: Partido de la Revolución Democrática.

** "Commercial sex workers" includes both male and female.

[a] INEGI, 2010.[38]
[b] Cuéntame INEGI, 2010.[62]
[c] CENSIDA, June 30 2010.[4]

While the number of participants taking part in this study is fairly small, most state programs have a range of two to twelve people working in their HIV/AIDS program. For this study, participation varied between one and seven subjects per state. In the state where only one person participated in the study, that person was the program chief. These small participation numbers mirror the current state of human resource investment in HIV/AIDS programs at the state level.

This study used a mixed methods approach to explore barriers and facilitators to data utilization. Participants completed a quantitative survey or participated in an in-depth qualitative interview. The subjects covered in the survey and the interviews were structured to cover the potential barriers and facilitators to data utilization under the rubric of the three main focus areas: macro political, resources and data characteristics. Both methods used the same broad topic areas listed below:

1. Program characteristics: MARPS in the state, program activities for prevention, decision-making around priority populations.
2. Macro political:
    a. Communications: methods, frequency and channels used for distributing data and research results within the organization.
    b. Organizational behavior: expectations from organization regarding data utilization, organizational investments in data utilization.
    c. Policy environment: laws limiting program activities, expectations and influence of local political establishment on program activities, local public opinion effect on programmatic decisions.
    d. Decision-making power: level of influence exerted by a variety of actors.

3. Resources: current resource availability for human, financial, technical and material resources, budgeting exercises, budget allocations in contrast with program priorities.
4. Data characteristics:
    a. Data collection, quality and relevance: program's participation in data collection and indicator selection, relevance of current indicators, perceptions of surveillance data quality and accuracy.
    b. Availability and accessibility of data: types of biological and behavioral data that are accessible to the program, channels for accessing existing data.
    c. Local capacity level: trainings and experience in data utilization, perceptions of value of data utilization.
    d. Data utilization process: methods and process by which data are incorporated into program planning.

Both the survey and interviews were conducted by the Principal Investigator. The survey was pilot tested in two different states in Mexico in order to ensure that the themes and questions themselves were applicable to participants' experiences. The survey was edited after the pilot test and before implementation.

CENSIDA maintains a publicly available list of the state HIV/AIDS program chiefs for all of the state HIV/AIDS programs. The Principal Investigator contacted the program chiefs for the selected states and invited them to participate. The Principal Investigator also asked program chiefs for recommendations of other officials in his/her state and within his/her program that might be eligible, interested and willing to participate in this study. These referrals were asked to participate regardless of the program chief's own decision to participate in the study. All participants, including referrals were approached for participation by the Principal Investigator via phone, email or in person.

Data collection took place between March and May 2010. In order to ensure confidentiality, participants selected a location of their choosing to complete the survey or interview. After explaining the purpose and objectives of the study, the Principal Investigator obtained informed consent from the participant and asked for permission to take notes during the session. Privacy and confidentiality were assured in order to reduce the possibility of respondent bias. This research was reviewed and approved by the Committee for the Protection of Human Subjects at the University of California, Berkeley.

DATA ANALYSIS

Data collection was conducted and analyzed in Spanish. For the qualitative interviews, extensive notes were taken and transcribed by the Principal Investigator. Interviews were not tape-recorded in order to reduce participant concerns about confidentiality. A codebook was developed analytically prior to data analysis based on topics from the three main issue categories. Additional codes were developed as new themes emerged from the interviews while data were coded. After the text was coded, materials were sorted by theme and then examined for patterns. Coding and analysis were conducted by the Principal Investigator using Atlas.ti (GmbH, Berlin 2011), a code-and-retrieve program used for analyzing qualitative data. Quantitative data were entered into Excel and basic frequency analyses were conducted in Stata.

The results of the qualitative analysis drove the quantitative analysis. Areas of agreement and disagreement around barriers and facilitators to data utilization were identified between the

qualitative and quantitative data and explored further. Areas with a lack of consensus are highlighted in the findings.

RESULTS

The results described below are introduced under the larger thematic categories that drove the research: macro political, resources and data characteristics. Barriers and facilitators to data utilization are then presented within each category. These represent findings specific to the activities of state HIV/AIDS programs. Although this study included respondents from *IMSS* and *ISSSTE*, there were not enough data gathered to assess these institutions' HIV prevention programs independently from the state programs based in *SSA.*

Quotations are used through this section to illustrate the experiences of participants. Minor changes have been made to some of the quotations to protect the anonymity of the respondent and/or the state program. Wherever the symbol XXX is seen, an identifying phrase has been removed to protect the respondent.

MACRO POLITICAL

Although a number of macro political themes were discussed with study participants, only a few emerged as strong issues facing state HIV/AIDS programs. The topics of communication between institutions in the health sector, the policy environment under which the programs operate, decision-making power for the program and broader organizational issues were at the forefront of participants' experiences.

Communication between individuals working on HIV/AIDS issues at different institutions is not formalized in these states, which presents a barrier to a sector-wide approach to HIV. Truncated communication hinders the potential to identify key areas on which to focus and establish coordinated efforts and activities between health systems. A more cooperative system would allow interested parties across the health sector to share data regarding their beneficiary population's needs and risks and establish targets that can be addressed jointly, such as testing and treatment of a shared population group like pregnant women. Although this type of communication is not necessary, it would provide an additional outlet for data to be used in priority-setting.

In the absence of a formalized system, communication channels and settings have emerged as a way for officials who are facing similar issues to interact, identify common problems and generate potential solutions. Two different modalities emerged in these states: interpersonal interactions and cross-institutional committees. These approaches have provided individuals with a forum within which to discuss emerging patterns in the data. Interpersonal interactions seem to be driven by personal connections between people who see each other on a regular basis in their work spheres or at conferences.

> *"Communication depends on personal interactions…Who knows who...[we] know each other from conferences. This interaction is not anything that XXX [my institution] promotes." –Treating physician*

Two states in particular mentioned cross-institutional committees that include all the major health institutions as well as other interested agencies at the state level. The development of these committees has been driven by the interest of officials working across the health sector to meet, share and discuss the issues that their programs are facing.

"Communications between SSA, IMSS and ISSSTE are good. The XXX [state committee] holds regular meetings, which include all the social security institutions and private hospitals…We discuss epidemiological emergencies such as H1N1, dengue, HIV or any other reportable disease…" –State epidemiologist

"[We] work in coordination through the XXX [cross-institutional committee for HIV/AIDS] for our state. It includes SSA, IMSS, ISSSTE, etc, PLWHA, other organizations with interest in the topic…It is organized by the state program. We present the current situation regarding budgets, prevention…Have monthly meetings for training: prevention and case review including all institutions." –Program chief

Even though these committees seemed to have arisen and are centered on epidemiological issues, they occasionally have led to setting programmatic direction. In one committee in particular, the meetings led to identifying a programmatic priority for authorities across the health sector.

"In this committee we have been focusing on detection and PMTCT [prevention of mother-to-child transmission], which led to a sector-wide agreement on HIV testing of all pregnant women." –Program chief

Thus, although there are no formal communications strategies required or espoused by the federal level, officials working in HIV in these states have developed mechanisms to minimize communication barriers. It is unclear whether these, or other, strategies have been implemented elsewhere across Mexico.

The second major issue that respondents are facing is related to the policy environment under which the state programs operate. Which political party is in power in state government did not appear to have much effect on a program's direction. However, smaller localities that are more socially conservative have a tendency to limit coverage of program activities and the types of services that can be offered. State program officials are often forced to find creative solutions to sell their activities to local actors in order to get approval or buy-in. Having reliable, local HIV surveillance data strengthens the argument for services that state officials can make. As in the example below, state program staff needed approval from the local clergy to sanction as well as provide additional legitimacy to their proposed activities with local migrants.

"In conservative municipalities, we have to find creative ways to reach the population. In one place, after a presentation introducing a research survey with migrants around HIV, the local officials stated 'Great. Let me check with the priest.'" –Program staff

Other officials have fallen back on the federal mandates that require state programs to work with vulnerable populations as their rationale for targeting at-risk groups. This gives them the regulatory authority on which to fall back in case of resistance from other actors.

"The program can work with at-risk populations because it is demanded by the federal level. Otherwise, there would be more barriers…There are still barriers in social communications which must be approved by the state prior to being released or published." –Program staff

Another, quite interesting, topic around policy environment is the role of NGOs in advocating for program activities. Two states mentioned that vulnerable populations that *do* have an outside organization advocating for services tend to receive programmatic activities. This is contrasted to lack of services for populations that do not have others generating attention and demanding support. In other words, organized advocates outside of the state government structure can and do pressure the state program to direct activities towards their preferred populations.

> *"Target groups like MSM, transgender, lesbians have been 'protected' [by interested NGOs] but other groups are lacking attention." –Program administrator*

> *"The state government cares about sexual and reproductive health…this support allows us more freedom to work and plan projects but we still have difficulties selling work in populations that have little political clout." –Program chief*

So far, the main NGO response around targeting activities has coincided with the epidemic profile in Mexico. NGOs supporting gay men, female sex workers and women have been the primary actors organizing around these issues. However, critical as well as emerging populations at-risk, such as injecting drug users, indigenous communities and migrants, are less well represented in the NGO community. This dichotomy places the burden of recognizing the needs of less visible groups entirely on state program staff, with the possibility of generating conflict with NGO advocates and other state health officials.

The third major macro political issue that respondents are facing is the level of decision-making power that the program officials and staff are allowed to exercise. Several participants argued that larger state programs have decidedly more freedom to define their targets and activities, implying that smaller state programs have to address the concerns of superiors as well as the local community when making decisions. Although decisions in larger programs can largely be made in-house with little input from other authorities, social marketing campaigns were often one area where local cultural norms and/or political pressures would come to bear on what campaigns could actually cover as highlighted in an earlier quotation and the ones below.

> *"In XXX [large state program] they developed ads for MSM, but they have specific services and a big CAPASITS [specialized care center]. They don't need to ask for permission." –Program chief*

> *"Some decisions are made by the program chief and the staff because they are aware of what is allowed and what is not… Sometimes the program chief has to do what the State Health Secretary wants, such as on issues around social marketing: what, how, when, with how much money." –Program staff*

> *"There is relative freedom to generate strategies and actions in the state program. This is definitely true within the program. As for outside the program, the Communications folks have to get all their work reviewed by the state…they may end up with negative feedback…One campaign [targeting MSM] was never released by the state… It is*

unknown how the State Health Secretary found out about the campaign, but he didn't like it…" –Program staff

These quotations suggest that social acceptability, in particular around social marketing campaigns, do come to bear on state program decisions. In particular, state health secretaries can play a role censoring perhaps in anticipation of pressures from community members.

In addition to these issues the potential leadership abilities of the program chief have a strong influence on what and how much the program can do. This was evidenced in particular by program chiefs who have taken on an advocacy role for the program's priorities and activities, sometimes resulting in adverse consequences for themselves.

"Individual program heads fight to expand services but it's based on the person." –Patient representative

"The former program chief was forced to resign after many years because of a [social marketing] campaign…This was combined with other issues, like political problems. The former program chief was very activist." –Program staff

The last macro political topic to be discussed is organizational issues, both around organizational behavior and structure. The two main organization issues are the relationship between the federal and the state levels, and how the placement within the state structure impacts programmatic characteristics.

CENSIDA's relationship with the states is structured around its role of stewardship and guidance inherent in its position as the national coordinating agency for HIV/AIDS issues. As such, *CENSIDA* can influence the state program and the local government through incentives as well as sanctions. However, many participants felt that the relationship with *CENSIDA* has been based on unrealistic expectations and is mostly one-sided in terms of benefits. Participants felt that *CENSIDA* expects state programs to have the same flexibilities in their work spheres as *CENSIDA* does, including access to resources to meet different mandates. Furthermore, recent crises have weakened the partnership. For example,

"CENSIDA treats state programs as though they have the same level ['nivel'] as CENSIDA does, but the state programs are not executors of their own budgets." –Program chief

"The feeling I get about CENSIDA is a focus on national research projects and national campaigns. They should have greater contact with the states and better coordination between Research and Prevention at CENSIDA…They are not present for the states: there is no advising or follow-up but they want reports back and the state's data." –Program staff

"The federal level establishes that state programs should work with vulnerable populations, but these populations are hidden and the organizational structure at SSA is not flexible enough to work with them…[Staff] won't do night work due to poor payment and salaries. It's a proposal to failure ['una propuesta al fracaso']." –Program chief

"Relationships between the states and the federal level are deteriorating: states are feeling attacked…" –Program chief

In the 2000s, the structure of state HIV/AIDS programs was fundamentally changed. The programs, which had been originally established as State Councils or *COESIDA*s, were transformed into health programs within the structure of *SSA* and the *SESAs*. This reorganization had significant impacts on programmatic activities, many of which were perceived as negative. All of the respondents who discussed this issue felt that *COESIDA*s were much stronger programs because their placement within the state government structure allowed them more independence to conduct their activities. The *COESIDA*s' status as a state council gave them priority, especially under budgetary procedures, compared to other state health programs. Furthermore, the independence and distinction of state councils allowed more decision-making power to be centered in the program.

"Rescinding the COESIDAs to SESA was a mistake because the state health system has tons of programs and HIV is just one more. Having a state council gives more weight to the program within the state." –Program staff

"Only Jalisco and Oaxaca remained COESIDAs, and all the others were absorbed into SSA at the state level…[Those two] were not absorbed because the program heads prevented it along with a lot of support from local NGOs…" –Program staff

"State councils are formalized and increase yearly. That is hard to dismantle now." –Program staff

RESOURCES

Experiencing a lack of resources within government programs, especially for prevention in public health, is not unexpected. However, participants described a series of specific issues that influenced how their program functioned including the budgeting process and resource allocation, prevention funding and in-kind support, and human resources. These barriers indirectly affect the potential for data utilization by taking up staff time that could potentially be spent analyzing data for program priorities. Some states are addressing the barriers they experience by developing alternative solutions to the problems they face and these are also discussed below.

In terms of the budgeting, participants from all states expressed frustration to varying degrees with different aspects of the process. State programs participate in a budgeting exercise every year that allows to them plan for program activities. During this exercise, programs are expected to take into account existing program activities as well as emerging issues in order to request the appropriate resources to address their needs. However, the approved budget rarely, if ever, meets the program's complete funding requirements, which frustrates program staff. The state program is then left to re-arrange their planned activities and expenditures to meet the new reality.

"[We] do budgeting exercises but what money is awarded has nothing in common with the budgeting exercise...Maybe this is related to the fact that the budget is essentially

based on the previous year's budget plus X% more. The budget increases every year but it is not related to the program's real needs…" –Program Chief

"[The state program] has difficulties around the state and local budgets. The will is there but the money is lacking." –Program staff

The frustrating budget exercise removes staff's incentives to use data to prioritize populations and program activities, especially if the program's budget will be primarily based on historical funding trends.

The second major complaint about the budget process was disbursement delays. Two states reported suffering delays—often every year. One participant went so far as suggesting that 80% of states suffer funding delays due to lack of planning at the state government level. The practical implication of this delay is that the program is then forced to complete any planned prevention activities in a shorter timeframe. Furthermore, any long-term prevention planning is dependent on a fluctuating budgetary and calendar cycle.

The two states that did not report having disbursement delays attributed this to their continued advocacy for the program's needs. Advocacy efforts are centered on the relationships the program chiefs have developed with other officials who have influence over the program's budgetary cycle. One program chief took a more conciliatory, relationship-building approach while the other was more aggressive.

"[I've developed] personal relationships with other government officials, like the Director of Finance and buyers, to facilitate the situation…State program staff give personal stories, talk about cases, give freebies like bracelets [to officials]. At a local storage site, program staff gave workshops on condom use. It has been more productive to sensitize more finance people than our superiors in the health sector…[we] have the relationships to request releasing the funds earlier in the year so that the activities don't have to be bunched up at the end..." –Program Chief

"…[my] program does not experience delays in having their budget released as other states do. This might be because I fight ['me peleo'] to get the money and have more support to begin with."—Program Chief

Since the Mexican government's commitment to universal access to ART, the majority of the resources have been diverted to funding, managing and procuring medications for HIV-infected patients. This has resulted in a steady decrease in prevention funding every year. Some states as well as *CENSIDA* have been addressing this by directing financial resources to NGOs and universities so that they may do the prevention work. The funding is often available through a competitive bid process that starts with a request for proposals (RFP), but projects are limited by which activities qualify for funding. One participant indicated that often NGOs cannot reapply to fund the second phase of an existing project, which compromises the potential continuity of successful activities and interventions.

This shift in funding from prevention to treatment at the federal level has not been met with a compensatory shift in funding at the state level, which has had serious implications for human resource allocation. Program funding provided by the local state government is primarily

used to cover operation costs and those are focused on treatment issues. As one respondent indicated, for small state programs, the lack of prevention-specific funding has serious implications,

> *"It is not reasonable to have only two or three people working in a state program. They spend their life doing medications ['se les va la vida en medicamentos'], and they can't do anything else." –Program staff*

While *CENSIDA* and federal authorities support state program activities by providing in-kind supplies, such as condoms and rapid tests, there is rarely any funding to support staff to conduct prevention activities beyond the baseline operational practices. Furthermore, staffing limitations are evidenced in other areas as well.

> *"[We] have a lot of data to explore, but we are unable to explore it because we lack an evaluation person…we want to know where there are deficiencies and sharpen the targeting of knowledge promotion…" –Program staff*

> *"There are not enough human resources, and HIV/AIDS is not a priority. There are programs, jurisdictions but the state manages <u>many</u> programs…" –Program staff*

Some state programs have taken a different route to accessing funding for prevention and additional activities: they are tapping into alternative sources of funding. They are working with other partners, including government agencies beyond the health sector, to identify their priorities and then seeking financing for activities on an individual project basis. This allows the program the flexibility to fund projects that are of interest without compromising their limited budgets.

DATA CHARACTERISTICS

A key element in improving surveillance data utilization is addressing any deficiencies in the data collection and distribution system itself. Barriers being faced by state programs include issues around feedback within the system, data relevance, accessibility and quality. Some states have addressed these issues by identifying alternative sources of information that can help them identify or confirm the vulnerable populations in their state.

The most commonly mentioned barrier centered on problems giving and receiving feedback within the health system about ongoing surveillance activities as well as special research projects. States that receive and administer rapid tests from *CENSIDA* must provide data from a form that collects information on the individual's demographic information and risk factors. Data from the forms are aggregated and submitted to *CENSIDA* for analysis. Respondents from three out of four states reported not receiving any feedback or analysis from *CENSIDA* on those data, except to ensure completeness. Similarly, states that have participated in specialized surveillance projects with *CENSIDA* and other agencies reported having difficulty accessing the data and research results after the project ended. Any feedback from the outside agency was usually shared through a presentation or channeled through the program chief.

This lack of dissemination is further evidenced in the development of projects and data collection forms. These are mostly developed by national institutions, such as *CENSIDA*, the

National Institute for Public Health (*INSP*) and others, and then data are collected at the state level. However, the needs of states are not always accounted for. As two respondents indicated,

> *"They [CENSIDA] often conduct project with the help from INSP…[They] develop these things without asking the states for their needs, they don't pilot at the state level…The result is a form with information that is too generalized..." –Program staff*

> *"[The] research structure is too centralized, it requires training, is led by interests rather than needs, few are focused on implementation strategies, and they are often driven by ART issues…" –Program staff*

This last quotation highlights the perception of state-level staff of the research infrastructure that exists around them. Specifically, this participant indicates that the current system for research is not meeting local needs both thematically and strategically. This perception is likely borne out of the experience in many states of research studies being developed centrally at *CENSIDA* and/or *INSP* with data collection taking place at the states.

A poor feedback loop between states and the larger health sector may be related to the complicated system for surveillance data collection, entry, aggregation and analysis that is currently in place. Depending on the state program's placement within the health sector and state government infrastructure, their access and responsibility for surveillance data may vary. Surveillance data are primarily generated around the country in health centers and other primary care facilities. Some state programs collect data from all of those sites and conduct the data entry and submission themselves. Others are responsible for the forms linked with rapid testing that are sent to *CENSIDA* while the Epidemiology Department of the *SESA* is responsible for the traditional surveillance forms. The latter category of programs represents a bi-furcated system where two agencies are responsible for different data sets going to different agencies. In order for these state programs to access surveillance data, they must make specific requests to the Epidemiology Department. This presents difficulties for the state program because it has the same programmatic responsibilities but limited access to the surveillance data that could help drive its decision-making.

> *"In order to get surveillance data, the program chief needs to request it from the State Lab [Epidemiology Department] but little is sent without prompting. I wish that there was an existing protocol for data feedback and for special requests. I don't know what the issue is around the data availability, but I assume it is related to lack of resources." –Program staff*

> *"[We] do analyses for the state program and the surveillance and research committees. Analyses are by request…We want to establish a protocol for what analyses are required by the state program and how often they should be sent." –State epidemiologist*

While on the topic of data collection and access, it is worth discussing the issue of data aggregation because there was a discrepancy between the qualitative and quantitative findings. While one state felt that data are disaggregated in a useful way, a different state identified data aggregation as a barrier to targeting their program activities. The latter state would like

surveillance data to be available by municipality in order to facilitate their work in smaller communities. For instance,

> *"[Our] program wants more information with more variables… The state surveillance bulletin has more information than CENSIDA, but there are no breakdowns by municipality, especially of AIDS cases…[We] could use municipality-level data to argue the epidemic profile—national, state, municipal—to municipal authorities." –Program staff*

The last important theme to emerge in this area was an unexpected one. Respondents from all of the states indicated that underreporting or misreporting of cases undermines the quality of the surveillance data in their state. Over the last ten years, Mexican authorities have taken great efforts to address issues of underreporting by seeking out miscounted cases, reducing duplication and educating physicians on the needs of accurately reporting cases of HIV/AIDS, especially at death. Nevertheless, respondents feel that underreporting is still an issue in their jurisdictions. Data from the survey further indicate that respondents do not trust the data quality for their state, and they believe that the surveillance data reflect their state's epidemic profile only somewhat or not at all. Interview respondents identified some potential reasons for underreporting issues such as stigma, lack of empathy from those collecting the data, and reporting requirements that are forgotten when the patient is transferred around the health system.

> *"Stigma leads to falsifying data by the patients themselves or they simply don't go to get the tests done." –Patient representative*

> *"Even after working 27 years with the HIV population, I'm still amazed that you find cases [i.e. cases are reported] only when they've died." –State epidemiologist*

> *"Surveillance data are not accurate because of lack of completeness, delays, doctors or epidemiologists fill out the form with no rapport with the patients…" –Program staff*

> *"If HIV testing is done at a local health center, the patient is often referred to the 2nd level or SAI [specialized care center] for reporting of the case, but the form for rapid testing is lost or never completed…" –Program staff*

> *"[Ten years earlier] a change in command of the program chief resulted in drops in data quality…Lower detection rates and less reporting due to the lack of trust in the new program chief." –Program chief*

As a way to address some of these barriers, three out of four states identified using alternate sources of information to meet their targeting needs. Two states are using service utilization data from their HIV/AIDS care facilities to identify needs in the community as well as emerging populations for concern. Others use data from other government agencies, such as census data and statistical and geographic information, to identify localities in need of activities. One state maintains its own database with the surveillance data so that they can conduct their own analyses.

DISCUSSION

The results presented here confirm findings in other studies about barriers and facilitators to data utilization as well as present new themes. I found the co-existence of obvious political barriers to data utilization as well as more subtle, structural and bureaucratic barriers that can also be very hard to change. Nevertheless, these findings identify key areas that can be leveraged to improve data utilization and overall program performance in the specific case of Mexico. These are reviewed below under the larger issue topics that drove the research.

In terms of macro political issues, the findings on communications indicate that current communications between health systems tend to be non-existent or *ad hoc*. In states where alternative forms of communication have developed, it has been driven by the efforts of officials working on HIV/AIDS issues because it serves their needs to have communication channels that cross institutional boundaries. These reports of interpersonal communications echo findings of an earlier study conducted in Mexico, which found that links between researchers and decision-makers through personal networks promoted the use of research in policy.[20]

As for the policy environment and decision-making power that form the context for these programs, two issues are worth highlighting. First, the mandate from the federal level that requires states to work with vulnerable populations is a mechanism that could be exploited further to ensure that prevention programming is directed appropriately and driven by data, not by political considerations. When faced with reticent political officials, program staff could use the federal mandates to support their work with those most at-risk, not just the most acceptable. However, one state's report that program decisions are preemptively influenced by what is acceptable indicates that program staff is already, even if unconsciously, allowing the local policy environment to influence programmatic decisions. As Lindblom would argue, program staff is ignoring "politically impossible and so irrelevant"[1] policy options because they know that superiors would not approve. It is unclear if in this situation the federal mandate could be used to successfully leverage a more radical program policy, but the potential for sanctions and incentives from *CENSIDA* does hold sway at the local level.

These findings raise an interesting dilemma over decision-making in the HIV/AIDS bureaucracy. Who should have final decision-making power over programmatic issues: program chiefs or higher level authorities like the State Health Secretary? Program chiefs are more likely to be better informed than the Secretary about the surveillance data that pertain to their program and most attuned to needs of local at-risk groups. State Health Secretaries, however, have more power and more responsibility. They oversee all health programs and face more of the potential stakeholders in the state's political arena and thus have to weigh more factors than data alone when making decisions. In the end, their power can also be felt by their influence over budget allocations. Given such a politically influenced scenario, it is not clear how data-driven program activities would be if the primary decision-makers where the State Health Secretaries.

Second, the issues of 'level' or '*nivel*' within the larger health and state government structure provide insight into the potential for decision-making at the state programs. This result echoes earlier findings by the Principal Investigator, which was conducted years earlier and in other states.[61] It appears that state programs that remained as COESIDAs have, in practical terms, more discretion over their program, its activities and direction than programs that became part of the state health system. State councils are allowed more independence and are more difficult to dismantle and shortchange than programs that have to compete with many other programs for funding and attention. However, it is difficult to determine what characteristic

drove two state programs, Jalisco and Oaxaca, to remain state councils: strength or independence. It is possible that these two programs were already strong enough, had enough outside support from NGOs and others, or had support from the political establishment before the reorganization such that they could better advocate for themselves to remain COESIDAs. Therefore, it is unclear whether the independence and strength evidenced by COESIDAs results directly from their different placement within the health system and state government structure or from inherent characteristics of the program and its staff.

The second area for discussion is the topic of resources. Budgetary issues present unnecessary barriers to planning and implementation. There is limited funding to support staff for data analysis and prevention program implementation, thus limiting the state program's potential reach. Paradoxically, programs could potentially advocate for greater resources, both financial and human, if they had the staff to analyze their surveillance data and underline the scale of their local epidemic. Furthermore, disbursement delays and reallocation activities duplicate efforts and make program staff frustrated. The efforts described by two program chiefs highlight the role of personal relationships in keeping the program afloat. Whether with vinegar or honey, advocacy by the program chief (and staff) can result in better budgetary conditions. One state's efforts in sensitization of finance officials have institutionalized the positive responses to their requests. Lastly, the current RFP process being used to fund prevention activities has some significant downsides by not representing a broader, more unified policy for prevention. This is particularly evident in the current structure of the RFP process itself, as described by respondents, because it promotes discontinuity of projects. Also, it is unclear how the projects that are funded through the RFP process complement, supplement or replace program activities by local authorities.

With regard to data characteristics, the lack of data dissemination echoes findings about poor communication throughout the health sector. Surveillance projects and systems that are developed to meet only the needs of federal agencies without adequately reporting back to states drain resources from the state with little benefit in return. Furthermore, not including states in the data analysis portion of research projects presents a lost opportunity to improve local capacity. Some states have responded to this lack of partnership by seeking out alternative sources of information and funding to address their needs. These should be additional sources for state programs not alternative ones. One potential strategy to improve data utilization is to provide access to disaggregated data, especially by geographic sub-divisions. This simple solution would help programs who want the data and cannot get them while not compromising programs who are content with the current availability.

An additional concern is that of data quality. The concerns reported by participants about underreporting of cases calls into question the potential accuracy and reliability of current surveillance data sources. With no direct measures of programmatic impact, such as HIV incidence, program managers are left to interpret (and over-interpret) existing surveillance data to try to assess how successful their prevention activities are. Issues of underreporting and interpretation can be partially addressed by improving staff training in data collection and program monitoring and evaluation. Giving local staff skills and tools for data interpretation would also provide program managers with an additional resource for advocating on behalf of the program to their superiors. However, it is worth considering that if programs doubt the accuracy of their surveillance data, they may be less interested in combating any of the other barriers that they face.

LIMITATIONS

This study is subject to several limitations. First, a small number of participants (and states) are represented in this research. However, given the relatively small universe of individuals eligible to participate in this study, these results closely represent the range of experiences in each of the study sites. Furthermore, several of the barriers and facilitators reported here echo those identified in earlier research conducted in other state programs.[61]

Second, it is difficult to assess the potential leveraging power that *COESIDA*s have compared to traditional state programs because only one *COESIDA* was included in this study. The inclusion of Oaxaca would strengthen the results reported here. However, since there are two *COESIDA*s and 30 other state programs, it is possible that the differential effect on independence between their structures could not be determined with certainty.

Lastly, the results from this study cannot be said to represent the experiences of all state HIV/AIDS programs in Mexico. Nevertheless, this research adds to the growing literature on programmatic HIV/AIDS activities in Latin America, at the sub-national levels of countries, and in relation to data utilization.

CONCLUSION

The barriers and facilitators identified by respondents in this study are not impossible to overcome. Any attempt to improve the utilization of data by local programs needs to take into account the difficulties that officials on the frontlines are facing, and opportunities for intervention and leverage should be maximized. The top priorities for addressing data utilization barriers should include formalizing inter-institutional communications, supporting state programs' efforts for data-driven advocacy and continuing efforts to improve data quality. But primarily, data utilization would be enhanced by improving local capacity for data analysis and addressing issues in data dissemination, such as ineffective distribution channels and lack of disaggregation.

It is important to note that in all of these states, many staff members have been committed to the program for many years. The role of program leadership and longevity cannot be minimized as new efforts are made to improve prevention activities. These programs will continue to function even through the limitations they experience. As the investment in treatment grows, corresponding efforts, such as those outlined above, are needed to help state programs reach their fullest potential so that targeted prevention can do its part in reducing the burdens of HIV/AIDS on people, their governments and their health systems.

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CHAPTER 3: THE UNINTENDED CONSEQUENCES OF ENFORCING EXISTING POLICY: A CASE STUDY OF HIV/AIDS PROGRAMS IN MEXICO

This study describes a specific case where the enforcement of an appropriate national policy has had unexpected effects on local programs. In recent years, an existing policy in Mexico that limits the sharing of antiretroviral drugs between states has been more stringently enforced with considerable implications for HIV/AIDS programs at the state level. The resurgent enforcement of the "no sharing" policy has limited decision space at the local level around drug availability issues. In this paper I argue that, combined with previously limited decision space around prevention activities, the potential for innovation at the local level will be stifled and program staff will limit the risk-taking and advocacy they are willing to engage in to improve program services. In essence, the enforcement of an existing policy on medication procurement has resulted in a concomitant loss of discretion at the local level which threatens the benefits gained in local decision-making by decentralizing the health system.

The Mexican health system is comprised of a combination of social security institutions, the Ministry of Health (*Secretaría de Salud, SSA*) and the private sector. Through the 1990s and into the early 2000s, the Mexican health system was decentralized. Within *SSA*, much of the responsibility for providing health care to *SSA*'s beneficiaries was devolved to the states. In practice, states are tasked with health care delivery and projections for medications and supplies while the purchasing is conducted by federal authorities in the central offices of *SSA* [for an extensive review of the Mexican health system and its decentralization see [41-43]].

In terms of treatment for HIV/AIDS, treatment recommendations and guidelines are established by an expert committee at the national level and disseminated locally. Actual treatment provision is conducted and managed at the state level. Antiretroviral therapy (ART) was first offered to persons living with HIV/AIDS (PLWHA) in 1993, but coverage was limited. In August 2003, *SSA* made a commitment to provide free ART to all persons with HIV/AIDS.[41] By 2009 it was estimated that about 71% of eligible PLWHAs were receiving treatment.[58, 59††] Of those PLWHAs receiving ART, about 51% are served by *SSA*.[55] In 2009 alone *SSA* spent over $75.5 million[‡‡] on ART to cover 32,400 patients, and those numbers have continued to grow.[63, 64]

SSA has a policy of "no sharing" of medications between states. This policy is in place to improve controls over inventory, limit corruption at the local level, hinder sales of government-funded supplies to black markets and force states to ensure that funding is properly accounted for. Until recently, this policy had not been enforced very strictly for HIV/AIDS programs. This allowed state programs to share, trade and borrow antiretroviral drugs in cases of unexpected shortages and to ensure that soon-to-be-expired medications would be used.[46] Beginning in late 2009, and partly linked to a government audit, the "no sharing" policy has been implemented in full force.

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†† This estimated was reached under WHO's 2006 ART guidelines. Under 2010 guidelines, which recommend starting ART earlier at 350 CD4 or less, Mexico's ART coverage rate drops to 54%.

‡‡ A historic exchange rate from December 2009 ($1USD/13.07 Mxn pesos) was used for this calculation.

State HIV/AIDS programs in Mexico provide an excellent case study for studying losses to decision space for two main reasons. First, programs are charged with two primary responsibilities of managing both treatment and prevention activities. Thus, there are two distinct areas where managers could be potentially exercising discretion over the program. Second, due to decentralization and the overall structure of medication procurement, state programs have the responsibility for delivering care and treatment to PLWHA but have limited capacity to procure the medications needed for these treatments. Even for program managers who are using data to make their decisions, e.g. number of persons taking ART, their choices are being limited or distorted by the policies put in place at the federal level. Additionally, under the decentralized model, state HIV/AIDS program staff members are state employees who answer to both state and federal authorities, which at times results in competing goals for the programs.

This case study focuses on the effect of the "no sharing" policy on the decision space of the officials who are managing the state HIV/AIDS programs. *Decision space*[5] encompasses the overall amount of discretion that managers can exert over their programs, and provides a useful framework to analyze how changes in discretion at the local level affect programs. In this paper, I will first provide the background on the antiretroviral drug procurement process currently in place in *SSA* and the role played by the lack of enforcement of the "no sharing" policy. This will be followed by a brief overview of decision space as it relates to this case. Following a description of the methodology, the results are presented and discussed in terms of the potential effects that enforcing the "no sharing" policy may have over the HIV/AIDS program's overall responsibilities.

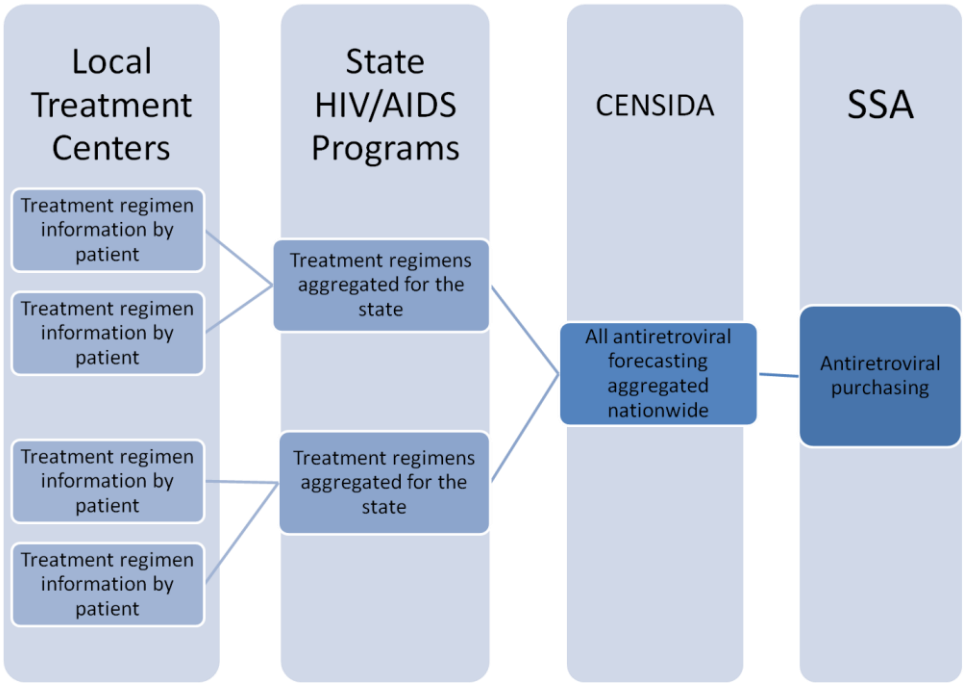
BACKGROUND

In this section I will discuss the current process and policies related to antiretroviral procurement in Mexico, including the "no sharing" policy. Furthermore, I will describe the strategies that state HIV/AIDS programs have been employing to work around certain policy restrictions that have practical consequences on the programs' functions. Lastly, I will present a brief discussion about decision space and how it is characterized in these programs.

ANTIRETROVIRAL PROCUREMENT PROCESS

Although decentralization allows for a fair amount of autonomy at the state level, antiretroviral planning is managed carefully from the federal level by the National Center for the Prevention and Control of HIV/AIDS (*Centro Nacional para la Prevención y el Control del VIH/SIDA*, *CENSIDA*). State HIV/AIDS programs are expected to update and maintain the treatment regimens of the patients on their caseload through tracking at the local treatment center (see Figure 1). The information on current treatment regimens is aggregated through a tracking system and forwarded to *CENSIDA* who centralizes projections, makes forecasts for antiretroviral drugs for all of *SSA* and coordinates the number and types of antiretroviral drugs that will be purchased. The forecasting and procurement process occurs twice year and is managed by *CENSIDA*, but actual purchasing is handled by a central purchasing office within *SSA*. The whole procurement and purchasing process usually suffers a three-month lag between the time *CENSIDA* places their order internally and *SSA* completes the purchasing.[46] Antiretroviral drugs are primarily purchased and funded by *SSA*, while states are responsible for other expenditures related to care of PLWHA such as treatment for opportunistic infections.

Figure 1. Forecasting and procurement process for antiretrovirals in Mexico.



The current forecasting and procurement system allows for adjustments of the original order at the mid-year procurement cycle but these are limited by law to no more than 20% over the original request. Therefore, states can make revisions (e.g. changes, increases, decreases) to their order if a review of their inventory indicates an impending shortage. However, the 20% restriction can be problematic for states where patient loads increase or ART regimens change unexpectedly, which is not uncommon for HIV/AIDS treatment.[46] Either of these situations can bring about shortages and stock-outs that could force patients to delay starting their treatment regimen or changing them. Delays and interruptions can result in patients developing resistance to first-line antiretroviral drugs with significant adverse effects to their health. Resistance to first-line antiretroviral drugs forces patients to second and third-line drugs that are costlier for *SSA* and more toxic for the patient.

The "No Sharing" Policy

The "no sharing" policy arose as a response to the complex system of contributions that fund medication procurement following decentralization. Federal contributions to health financing, including medication purchases, are now determined on the basis of a formula which takes into account the number of people receiving care in each state through the public sector insurance scheme, *Seguro Popular*, as well as performance and progressivity indicators.[41] Given this structure, the "no sharing" policy is aimed at restricting purchases made with one state's federal allocation from being transferred, shared or exchanged with another state. However, antiretroviral drugs are unique in that they are covered by the Fund for Protection against Catastrophic Expenses *(Fondo de Protección contra Gastos Catastróficos, FPGC)*, which covers expenses for a few high-cost interventions including treatment for childhood cancers, cervical cancer and HIV/AIDS.[41] Since medications for these illnesses are covered through a central fund, accounting for expenditures is more difficult because the contribution from the *FPGC* (i.e. the federal level) on behalf of each state is hard to untangle.

The current system for antiretroviral forecasting and procurement places two specific limits on state programs in charge of providing care: a process that is not responsive to time-sensitive requests and a legally-mandated restriction on increasing antiretroviral orders. Given

these barriers, states occasionally find themselves in a situation where they have medication shortages or medication surpluses and no formalized, structured mechanism to address them. Treatment centers within the same state can "borrow" from each other. This process had been facilitated through a page on *CENSIDA*'s website where clinicians could report shortages. However, the "no sharing" policy does not permit inter-state borrowing. Prior to 2010, while the policy was not being enforced, states reported contacting each other directly or individuals at *CENSIDA* that could help identify other programs or treatment centers in Mexico that could provide needed medications or could take on surplus ones.[46]

States circumventing the "no sharing" policy were driven by the practical challenges they were facing at the local level. The combination of the procurement cycle and the guarantee for universal access to ART placed states in a complicated position. They are part of a system that is not flexible to changing needs, such as shifting treatment regimens, but which at the same time guarantees the availability of medications to patients. Treating physicians and program chiefs feel pressured to provide the appropriate care for their patients so they find antiretroviral drugs however they can. At the same time, they want to limit wastage so they seek out others with whom they can trade soon-to-be expired medications.

In late 2009 the procurement of antiretroviral drugs came under scrutiny at the federal level. An audit of antiretroviral forecasting and procurement by federal authorities indicated that *CENSIDA* had purchased an excess of antiretroviral drugs amounting to over $18 million.[65] The audit also singled out the inter-state medication exchange mechanisms that had arisen while the "no sharing" policy was not being enforced. This has resulted in a stricter enforcement of the "no sharing" policy as well as the replacement of key staff members within *CENSIDA*. During the audit process, the antiretroviral procurement process was frozen, which resulted in delays in the disbursement of supplies to states and consequently to patients. In fact, the purchase of antiretroviral drugs for 2010 was not approved until May 2010.[66] The direct, practical result of the audit has been that states are considering flouting the "no sharing" policy again in order to ensure that their patients do not disrupt their treatment regimens while the current situation corrects itself.

DECISION SPACE

To begin this discussion on decision space, I will first use the *principal agent* approach to outline the relationship between the federal and state levels after decentralization. This is followed by an examination of the concept of decision space and previous applications of the concept in other developing country settings. Lastly, the role of *fit* will be explored as a complement to decision space. These approaches were selected because they help explain the relationship between the federal and state level, the range of choices that state actors are able to fully exercise and how managers respond to new constraints.

Principal agent describes two actors at work: a "principal" who has specific objectives to be met and "agents" who implement the activities needed to achieve those objectives.[5] Under this approach, the principal and the agents have some shared goals, but the agents have additional, self-serving interests that also need to be met.[5] Furthermore, agents have more information about issues at the local level giving them the incentive to pursue their own agenda outside of centrally-mandated responsibilities. To counteract the information imbalance the principal implements incentives and sanctions to guide the agents' activities. Ideally, regardless of which mechanisms the principal uses to control local activities, whether inspections, contracts or regulations, these will not dampen efficiency or innovation.[67]

For the decentralized Mexican health system the principal is the federal *SSA* authorities who want to maintain a healthy population and the agents are the state health authorities in charge of implementing the necessary activities locally that improve the population's health. Arguably, one of the benefits of decentralizing a health system is to maximize local knowledge and accountability in order to improve service delivery but that may come at the expense of overall goals and outcomes for the country. For our purposes, the limits on increasing procurement orders and the "no sharing" policy are the mechanisms by which the federal *SSA* authorities impose some control over how individual states make decisions.

In order to account for the roles that actors at different levels are playing, Bossert drew on the concepts of principal agent and "discretion" from public administration to define a new term called **decision space** and applied it to the public health sector.[5] Decision space is defined as "the range of effective choice that is allowed by the central authorities (the principal) to be utilized by local authorities (the agent) (p. 1518)."[5] In effect, decision space for local authorities is defined by the amount of discretion they can exert over the functional areas they oversee. That discretion can be mapped through formal elements that are made up of rules, regulations and laws (i.e. *de jure* decision space) as well as the amount of discretion that local actors exercise in practice (i.e. *de facto* decision space).[68] Just as rules may or may not be enforced by central authorities, local authorities may or may not choose to follow them.[5]

Bossert argues that decentralization gives agents a wider decision space to "take advantage of the new powers (p. 1523)"[5] at their disposal and innovate by making new choices that were previously unavailable. Agents can also choose not to change their programs at all. Innovations can be temporal, functional and structural. Temporal innovations are based on decisions that were not possible before decentralization, such as defining local prevention campaigns.[5] Functional innovations relate to leveraging a wider decision space in one functional area even if the decision space is limited in others.[5] Lastly, structural innovations arise from localities that have more discretion than others by virtue of their structure and relationship to central authorities.[5]

In a comparative study in Pakistan, Bossert and Mitchell evaluated the decision space, institutional capacity and accountability of 17 districts in four states that were at different points in the decentralization process.[68] These districts had differing degrees of authority and management even though their *de jure* decision space as defined by law was the same. In this study, three dimensions of decentralization—decision space, institutional capacity and accountability—were assessed simultaneously over a range of administrative functions, including service delivery and resource management.

The results from this study highlight a number of important issues. First, even though the *de jure* decision space was the same in all provinces, district officials were exercising a varying amount of choice. This suggests that the *de facto* decision space that local officials enjoy is not necessarily linked to powers derived from devolution of authority from decentralization. Second, in terms of decision space and institutional capacity, respondents reported consistent amounts across health functions. For example, if respondents reported wide (or narrow) decision space in service delivery functions, they also reported wide (or narrow) decision space in planning functions. Bossert and Mitchell suggest that it is possible that local actors reporting greater decision space are learning that as they effectively take on more authority in one health functions, they can also do the same in others.[68] The importance of institutional capacity in implementing decentralization is also highlighted although it is not clear whether actors are gaining more capacity by exercising more decision space or vice versa. All in all, this study

found that districts who used more of the decision space or had greater institutional capacity were more likely to take risks and innovate.[68]

Applying decision space to state HIV/AIDS programs, I will focus on the programs' two main functions: treatment and prevention.[§§] The program chiefs are at the center of responsibility and must meet goals for both. Within the treatment and care arena, programs have enjoyed a wide decision space. Forecasting of antiretroviral need is based on patient loads and treatment regimens that are followed locally. Although individual treatment regimens follow guidelines established at the federal level, patient care is not micromanaged, and regimens can potentially deviate from the guidelines if necessary. Furthermore, the program chief is the central decision-maker for state-funded purchases of medications needed to treat opportunistic infections as well as additional antiretroviral drugs used to supplement federal purchases.

As for prevention, program chiefs have had historically narrow decision spaces. This difference is primarily based on two factors. First, the HIV/AIDS programs are dependent on the state's government, infrastructure and support to function. Local political pressures and social acceptability go a long way in promoting progressive or regressive prevention activities. Second, resources dedicated to prevention have been dwindling steadily, which have limited the program's ability to reach those most at-risk for infection in their states.

While the *de jure* decision space is formally defined by treatment guidelines and prevention plans, there is also a range of *de facto* decision space. Within the treatment arena, the non-enforcement by the federal level and ignoring by the states of the "no sharing" policy expands the range of options available to states. As for prevention programming, the local policy environment in each state has considerable influence over the range of prevention activities that local authorities can implement (see Paper 2 for more information).[40]

There are two types of innovations that Bossert describes which are useful here: functional and structural. State programs could implement functional innovations by using the greater discretion they have in the treatment arena compared to what they have in the prevention arena, as they did when they shared antiretroviral drugs against existing policy in order to bypass ordering restrictions. As for structural innovations, although all HIV/AIDS programs were originally established as state councils within the state government structure, most state councils were transformed into traditional programs and incorporated into the health infrastructure. Only two out of the 32 state HIV/AIDS programs continue to function as state councils as opposed to strictly state programs within the state health structure (*Secretaría Estatal de Salud*, *SESA*). This distinction gives those two state councils, or *COESIDA*s, more autonomy within the state government structure. Arguably, the autonomy of the *COESIDA*s grants them a greater decision space within which to innovate.

Building on and complementing decision space, the concept of **fit** highlights how managers adapt to improve performance. Fit is drawn from contingency theory and relates to alignment within an organization, such as in strategy and structure, as well as alignment external to the organization, such as matching a structure to the environmental context or needs the organization is facing.[69] The key argument of fit is that alignment within and outside an organization can enhance performance, and potentially provide a basis for sustained strategic advantage.[69]

[§§] State HIV/AIDS programs in Mexico are also responsible completely or in part for surveillance activities. These activities are centrally mandated and closely proscribed, and states have little discretion in the execution of these activities so they will not be addressed here.

Peteraf and Reed's article of discretion and fit in the airline industry is particularly illustrative for this case study.[69] They studied airline managers' administrative practices in view of the constraints posed by government regulation. They found that removing regulations is not the key to improved efficiency; instead, the key is to match administrative practices to the current constraints, even if the practices are "not the most advanced, enlightened, or sophisticated practices available (p. 1091)."[69] In other words, fit is maximized when managers change their practices to match their new reality and accommodate the new constraints, demonstrating an important adaptive capacity in the managers. Furthermore, Peteraf and Reed argue that when a manager's discretion is constrained in one area, s/he offsets this by leveraging the greater level of discretion they may have in another area, which echoes Bossert's suggestion prediction about functional innovation.[69]

This is particularly relevant for our case study because it suggests that if HIV/AIDS program chiefs adapt to the constraints placed on their programs, they could potentially maximize their resources and outcomes. Furthermore, if a program chief's discretion is limited in one area, such as prevention, they can compensate by leveraging the broader discretionary powers they enjoy within the realm of treatment and care. I will argue that while the first point is likely accurate, the second is unlikely to occur given the enforcement of the "no sharing" policy and the resulting restrictions on overall decision space for program chiefs.

METHODS

STUDY SITES AND PARTICIPANTS

Four study sites were included in this case study to represent the variety of state programs and epidemic profiles in Mexico. The states will not be identified explicitly in order to protect participants' confidentiality but a comparison of important demographic characteristics is included in Table 1. The four participating states represent a variety of points within each indicator range, with the number of PLWHA receiving ART and the number of HIV/AIDS treatment centers worth noting.

Table 1. Study site comparison

	Population, 2005[a]	% Urban [b]	PLWHA receiving ART through SSA [c]	Most At-risk Populations[*]	HIV/AIDS Treatment Centers [d]
State 1	Over 6.5 million	86%	2000-3000	CSW, MSM, "Gay", Indigenous	4-7
State 2	Over 14 million	87%	3000-4000	CSW, MSM, Migrants, Indigenous	4-7
State 3	Over 8.5 million	99%	4500+	CSW, MSM, "Gay"	8+
State 4	Over 2 million	86%	350-500	CSW, IDU	1-3

[*] "Commercial sex workers" includes both male and female.

[a] INEGI, 2010.[38]
[b] Cuéntame INEGI, 2010.[62]
[c] Boletín SALVAR No. 10, 2010.[70]
[d] *CENSIDA*, 2010.[71]

Twelve interviews are included in this case study. Participants were selected using purposive sampling on the basis of their experience with and knowledge about the HIV/AIDS programs at the state. Participants included persons working at the state program in program planning, program management, surveillance data collection, analysis or use and resource allocation. Any staff member holding a position with one of these job responsibilities was asked to participate.

While the number of participants taking part in this study is fairly small, most state programs have a range of two to 12 people working in their HIV/AIDS program. For this study, participation varied between one and seven subjects per state. In the state where only one person participated in the study, that person was the program chief. These small participation numbers mirror the current state of human resource investment in HIV/AIDS programs at the state level.

CENSIDA maintains a publicly available list of the state HIV/AIDS program chiefs for all of the state HIV/AIDS programs. The Principal Investigator contacted the program chiefs from selected states and invited them to participate. The Principal Investigator also asked program chiefs for recommendations of other officials in his/her state and within his/her program that might be eligible, interested or willing to participate in this study. These referrals were asked to participate regardless of the program chief's own decision to participate in the study. All participants, including referrals were approached for participation by the Principal Investigator via phone, email or in person.

This case study was initially focused on the experiences and investments in prevention for the state HIV/AIDS programs. Study participants were asked questions regarding the macro political, data characteristic and resource factors that influenced programmatic activities. During the interviews, the current state of antiretroviral forecasting and procurement and its implications for state programs came up as a topic for discussion. Once the topic was raised more than once, participants were asked to delve further into the subject.

Data collection took place between March and May 2010 with additional phone interviews in February 2011. In order to ensure confidentiality, participants selected a location of their choosing to complete the survey or interview. After explaining the purpose and objectives of the study, the Principal Investigator obtained informed consent from the participant and asked for permission to take notes during the session. Privacy and confidentiality were assured in order to reduce the possibility of respondent bias. This research was reviewed and approved by the Committee for the Protection of Human Subjects at the University of California, Berkeley.

DATA ANALYSIS

Data were collected and analyzed in Spanish. The Principal Investigator took extensive notes and transcribed them afterwards. A codebook was developed analytically prior to data analysis based on topics from the original study focus. Additional codes were developed as new themes emerged from the interviews while data were coded. After the text was coded, materials were sorted by theme and then examined for patterns. Coding and analysis were conducted by the Principal Investigator using Atlas.ti (GmbH, Berlin, 2011), a code-and-retrieve program used for analyzing qualitative data.

RESULTS

The limitations in the procurement process combined with the "no sharing" policy have limited the potential avenues that state programs have to address impending antiretroviral shortages. As the "no sharing" policy has been fully enforced, state programs' decision space has been curtailed through two major trends, which will be explored in this section. First, the new pressures around antiretroviral procurement and sharing have weakened the relationship between the federal and state levels. Second, state programs have experienced a recent loss of resources and support from the federal level. These trends are likely to undermine the goals of decentralization. In this section, I will also address the particular case of the *COESIDAs* who, due to their independent placement in the state health structure, may experience lesser constraints on their decision space.

THE RELATIONSHIP BETWEEN THE FEDERAL AND STATE LEVELS

As the "no sharing" policy has been enforced in full, the relationship between *CENSIDA* and the state programs has been deteriorating, especially around organizational support and resources. Changes in policy and personnel following the 2009-2010 audit have had a negative impact on the relationship as federal officials question decisions made at the state level, further reducing the potential decision space that programs can exercise.

The following example underlines how increased scrutiny at the federal level has resulted in increased scrutiny for the states. Although *SSA* purchases the vast majority of antiretroviral drugs for PLWHA receiving treatment throughout its system, states are responsible for funding other elements of patients' care. States have been purchasing additional medications to meet those needs, and many state programs have been buying additional antiretroviral drugs to supplement the purchase from *SSA*.

> *"During a meeting with CENSIDA another state was called out regarding their spending on antiretrovirals with state funds. 'Why is the program buying duplicates of antiretrovirals already purchased by CENSIDA?' State programs buy duplicates to support purchases from the federal level and to establish a cushion they can rely on when there are shortages. Now states are being questioned in a negative way about how they spend their state money. I and others felt that after the other program chief was questioned, it could have easily been one of us who was questioned that way." –Program chief*

Adding to the uncertainty, key staff members in the treatment and care branch at *CENSIDA* were replaced after the audit. Participants indicated that the new officials at *CENSIDA* did not seem to understand the issues state programs were facing. As one state official stated,

> *"The current program head [for treatment and care at CENSIDA] does not have good communication channels with the states…[I] had to explain to the program head why another state was making additional requests to their original order of antiretrovirals…[I] had to explain that patients' treatment regimens may change during the course of the year and stocks need to be adjusted accordingly." –Program Chief*

As state officials experience mistrust and lack of content-area expertise from the federal level, the likely consequence is that state programs will continue to share medications. They will do so

more stealthily or risk patients not being able to start or modify their treatment regimens in a timely manner.

It is likely that state programs are feeling pressure from *CENSIDA* that is likely a result of pressures that *CENSIDA* itself is feeling. Instead of sharing sense of struggle, the relationship between them has been deteriorating. In addition to its responsibility for purchasing antiretroviral drugs, *CENSIDA* was also responsible for paying for laboratory tests performed at the state level, such as CD4 counts and viral loads, for a short period of time. While the audit was underway the budget for antiretroviral drugs and laboratory tests was frozen. Delays in payment to the local laboratories caused some facilities to turn patients away. In case of any medication shortage or denial of care, patients are encouraged to call the *SIRSEC* hotline managed by *CENSIDA* in order to report potential human rights abuses.

> *"When patients were turned away for their labs [due to lack of payment from CENSIDA], patients called the SIRSEC hotline to complain. The SIRSEC staff referred patients to me so that I could resolve the problem. They also said that if I didn't resolve it, patients should call SIRSEC again so a complaint could be formally lodged against me. In the meantime, local NGOs and I had already intervened with the labs and gotten them to continue service. So, patients [who called us] were re-referred to get their labs done. I asked another colleague to call SIRSEC to confirm patients' reports and my colleague was told the same thing…I sent a letter with copies to XXX and others questioning and complaining of the ethics of this situation. I seriously question: Is CENSIDA on my side or not?" –Program chief*[***]

These examples illustrate an unexpected change in the relationship between *CENSIDA* and the states. These interactions do not suggest the collaborative atmosphere that participants reported was present before the 2009 audit. Furthermore, as programs begin to feel that they are losing organizational backing from *CENSIDA*, they are less likely to take risks with other stakeholders in the state.

In addition to drops in organizational support, states have experienced issues with resource support as well. There have been delays in receiving medications that have practical consequences at the state level. One program chief indicated that over the last year,

> *"The relationship [with CENSIDA] is different [than previous years]. The response is slow. In terms of treatment, all the procedures are slower now. Before it was faster…The receipt of medications: it used to be timely, now it varies but it is not timely." – Program Chief*

As for prevention, decreasing in-kind support from *CENSIDA* has left state officials in a more vulnerable position. Through 2009 *CENSIDA* provided states with rapid tests and condoms to support prevention activities at the local level. Some states supplemented those supplies with additional outside funding. However, regular availability of these materials was an issue reported by participants in early 2010,

[***] Wherever the symbol XXX is seen, an identifying word or phrase has been removed to protect the respondent.

"Condoms are received only for vulnerable populations from CENSIDA and the state government…There are never enough. The same is the case for rapid testing and syphilis testing." –Program staff

"From the federal level [we received] rapid tests and condoms in 2008. Not funding for these, just the materials." –Program chief

"The program gets in-kind support from the federal level, but state money is almost exclusively spent on staff, and HIV/AIDS is not on the agenda for the state government." –Program staff

"[We] spend money on prevention that primarily comes from the local government, some from other government entities, also XXX Foundation." –Program chief

However, the in-kind support for prevention has disappeared and states are now expected to fund their own prevention materials. This is especially difficult in a funding climate at the state level that already did not place high priority on the HIV/AIDS program. As one participant indicated in early 2011,

"With respect to prevention, the delivery of materials is none. Before we did receive materials…The rapid tests are no longer funded by the federal level. Not this year, nor in 2010…I assume it is because of the lack of budget. Now those materials are paid for by the state. We make a request and hope it gets honored. Up until now it is being honored…All the prevention materials are through the state. The antiretrovirals through the federal level." –Program chief

The deteriorating relationship between *CENSIDA* and the states is likely to exacerbate the loss of discretion that states are feeling as a result of the "no sharing" policy. Although this study cannot quantify the negative outcomes for patients on ART that have resulted from enforcing this policy, it is clear that delays in medication deliveries undermine the goals of the "no sharing" policy by creating situations where program chiefs need to address impending shortages with little recourse.

COESIDAS AS AN EXCEPTION

COESIDAs represent a potential exception in this case. Their position as higher capacity programs may insulate them from a loss in decision space. Participants identified the two remaining *COESIDA*s as having more independence within the state government structure suggesting that their decision space is wider than other, more traditional state programs.

"There is relative freedom to generate strategies and action in XXX state council." –Program staff

"In XXX [state council] they developed [prevention] spots for MSM but they have specific services and a large treatment center…They don't need to ask permission." –Program chief

"Rescinding the COESIDAs to SESA was a mistake because SESA has tons of programs and HIV is just one more…Having a state council gives more weight to the program within the state." –Program staff

The wider decision space makes it possible that the enforcement of the "no sharing" policy will not be as significant for the *COESIDAs* as it will be for the other programs. Furthermore, the *COESIDAs* may have more discretion within prevention than their counterparts, which they could leverage in view of any loss in discretion in treatment. However, it is likely that the losses in organizational support and in-kind resources will have an equally detrimental effect on the *COESIDAs* as they have had on traditional state programs.

DISCUSSION

Prior to the enforcement of the "no sharing" policy, medication sharing and borrowing was tolerated because both the principal, i.e. the federal level, and the agent, i.e. the state programs, had compatible goals: getting the correct medications to patients on time. This compatible goal made their relationship more effective in achieving that goal[5], and the means to achieve that goal were more flexible. The practical result was that medication sharing took place. *CENSIDA*'s role in this informal system of inter-state sharing is unclear. At times, they provided tacit support by ignoring the sharing that was taking place while at other times, their support was explicit by linking states in need with states in surplus.[46] However, once the "no sharing" policy began to be fully enforced, the principal and agent goals were only nominally aligned causing the federal level to be concerned with ensuring that no medications are shared first and foremost, while the state programs' primary concern is ensuring access to medications on a timely basis.

Enforcing this policy was completely appropriate and within the regulatory parameters for the federal level. Nevertheless, enforcement resulted in a series of unintended consequences that will likely have greater impacts than the original non-enforcement had. It must be recognized that state programs were circumventing the "no sharing" policy because there was no existing mechanism to address emerging needs, such as using soon-to-be expired medications and sudden changes in antiretroviral forecasts from increased patient loads or changes in treatment regimens. By enforcing the "no sharing" policy and not addressing this gap in the procurement system, states have been left with a problematic situation and no mechanism to tackle it. State programs are still facing potential interruptions in patients' treatment regimens and taking a risk that their patients might develop resistance to the main antiretroviral drugs in their arsenal.

In addition to the adverse health effects, the second, and quite significant, unintended consequence of enforcement has been the negative effect on decision space for state programs. By limiting the potential avenues that state officials had to ensure antiretroviral availability, the federal level unwittingly constrained the state's programmatic decision space. Losing decision space in an area where it was previously enjoyed is likely to have a chilling effect on the possibility of innovation within the program overall. In fact, it could be argued that by circumventing the "no sharing" policy, state programs were using their enhanced decision space in the area of treatment to develop an innovation that addressed the constraints of the procurement system to ensure timely ART provision for patients with wide choices of antiretroviral drugs. This avenue is now no longer available.

Bossert and Peteraf and Reed would suggest that in order to compensate for the loss of decision space in the treatment arena, state program chiefs would compensate by aiming to exercise more discretion in prevention. However, I would argue that losing decision space in treatment makes exercising discretion in prevention less likely for these programs for two reasons. First, the shift in discretion from treatment to prevention will not happen because the decision space around prevention was already limited prior to the new limits being imposed in treatment. Thus, now all programmatic areas are facing decision space constraints limiting the potential for innovation. Second, the state programs have lost organizational support in the one programmatic area that already had a wider decision space. As *CENSIDA* and *SSA* question motivations and expenditures, the programs' potential for advocacy within state government erodes. Furthermore, given the Mexican government's guarantees to universal access to ART, treatment is the programmatic area with the legal backing to continue supporting its funding. When state programs feel protected and supported by the federal level, they are more likely to take risks programmatically and with their superiors at the state level. The limits on decision space and the decline in organizational support are constraining innovation at the state level, thus counteracting the potential gains from decentralizing the health system.

When a principal enforces a policy, how it plays out in the field often depends on the agent and its capacity level. As Peteraf and Reed point out, if program chiefs can develop new administrative practices that match the new constraints, they may be able to reduce the effects of the loss in discretion in their programmatic outputs. It is hard to determine whether administrative practices can change given the restrictions of working in the public sector. Adaptive capacity among managers seems more likely at the *COESIDAs* because those two programs already experience a wider decision space. However, when innovative potential has nowhere to go, even medium and high capacity actors may be constrained to the point where they can no longer make use of that capacity.

LIMITATIONS

This study is subject to several limitations. First, a small number of participants (and states) are represented in this research. However, the relatively small universe of individuals working in state HIV/AIDS programs suggests that the number of participants in this case study reflects the number of staff working in these programs. Furthermore, given the differing demographic and epidemiological dynamics of the states in this case study, the consistency in participants' responses suggests that the struggles experienced by these programs is widespread and likely shared nationwide.

Second, decision space was not the original research focus of this study. It was a topic that emerged organically when participants' described their experiences within their programs. Once the decision space theme emerged as a salient one, all of the subjects who had participated earlier where invited to re-engage with the Principal Investigator. All invited subjects participated again and provided their impressions and experiences around these issues.

Lastly, the timing of this research overlapped with the enforcement of the "no sharing" policy. Therefore, both the enforcement itself as well as the consequences resulting from that enforcement were being evaluated in a time of flux for federal and state authorities. Nevertheless, the findings from this case study add to the growing literature on decision space within the public health sector.

CONCLUSION

In theory, the decentralization of health services allows states a greater decision space to implement their programs and activities while still meeting the goals of the federal level. The policy limiting sharing of medications across states in Mexico formed part of decentralization by addressing problems stemming from corruption and poor planning. The enforcement of the "no sharing" policy around antiretroviral drugs is meant to target those issues, but it has also had unintended consequences. Specifically, it has narrowed the decision space of the state programs that are responsible for managing the HIV/AIDS services at the local level.

Decentralization gave states the option to keep their programs the same or to innovate within the new parameters. However, these new limits on the range of choices available to program officials essentially rescind part of the earlier gains and will have a stifling effect on exercising decision space overall. Because the *prevention* decision space was limited before and new limits on *treatment* decision space have been added in, this results in a net loss of discretion for these programs. Furthermore, enforcement has resulted in only a nominal alignment of goals between the federal and state levels, leaving state programs with little of the outside support needed to advocate for their activities within the state infrastructure.

This case study posits that the new limits on decision space in the treatment arena will not be offset by exercising the decision space within prevention. A follow-up study should evaluate if program chiefs are able to expand their prevention decision space as well as studying what effect these changes have on overall decision-making power at the state level. Additionally, an evaluation of administrative practices within state programs and how they might change to meet new restrictions would also be relevant. Lastly, a comparative study similar to Bossert and Mitchell's research in Pakistan could assess the net effect of the "no sharing" policy on decision space and innovation between the two *COESIDAs* and their traditional counterparts.

The experience of state HIV/AIDS programs in Mexico identifies an area of study that is not sufficiently understood. Specific constraints on antiretroviral sharing have had significant consequences at the programmatic level and it is likely that growing limits on decision space will have programmatic effects as well. It is important for future research and policy development to take into account the effect of policies that stifle the potential for innovation of local implementers and that limit the risk-taking and advocacy that program staff is willing to engage in to improve their services.

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CONCLUSION

The research presented in the three preceding papers explores what goes into making public health decisions and how that process can be informed by data. The first paper provides an in-depth look at how macro political, resource and data characteristic factors influence decision-making, surveillance data utilization and each other. The second paper identifies issues around communication and decision-making power arising from tensions within the health structure, budgeting and resource allocation processes, which are neither flexible enough nor sufficient to meet programmatic needs, and issues with the quality and dissemination strategies for surveillance data that influence utilization. Finally, the third paper explores how state programs have lost decision space in the treatment arena following the enforcement of the "no sharing" policy. When this loss is coupled with limited decision space in the prevention arena, I predict that innovative potential overall for state programs will decrease. Thus, enforcing an existing and appropriate policy may reverse gains in local decision-making power and initiative that were achieved through decentralization. In summary, these findings suggest that even if data are reliable, relevant and accessible, a number of barriers could still prevent data-driven decisions, in particular resource and political environment constraints. However, strong, well-informed actors have the potential to overcome these barriers by advocating for better programmatic decisions.

While this dissertation has focused on using data to drive decision-making, there has been little room for the on-the-ground knowledge that local actors are generating every day. The poor access to relevant data reported in the second paper could be counteracted by the experience of local program staff in reaching their target populations. Even though surveillance data and research are preferred when setting priorities for prevention in HIV, in many settings data are often lacking and other factors get in the way, so what role can experience play in defining program targets?

Conducting research in this arena has made me acknowledge that we are ignoring a potential wealth of information by focusing solely on data-driven decisions. There may be more than one pathway to priority-setting and achieving adequate, even good, prevention programs. One pathway is the model from academics and researchers, including me, that the best programs arise from data:

Pathway A: Data → Practice = Good program quality

A different approach acknowledges the realities that data and research results are often lacking, inconclusive, unreliable and other factors also get in the way, so what is the potential for good programs to arise by harnessing experience:

Pathway B: Experience → Practice = Good program quality?

Although experience cannot fully replace data, there are several relevant sources of information that can contribute a great deal: interest groups, institutional memory and longevity. Although biased, interest groups such as the NGO community can identify gaps in service—what's missing in prevention—because they are closely monitoring what activities their

constituents are and are not receiving. NGOs can also function as an alternative channel for drawing attention to program and resource shortages in ways that government officials cannot. In fact, Carol Weiss suggests that policy makers prefer receiving information from interest groups because they have an existing relationship and they can account for the groups' biases when processing information.[1] The second and third sources of experience are related: institutional memory among program staff and managers and an individual's longevity in a topic area or program. Both of these sources relate to the historical experience that program officials gain from being immersed in a program or content area over a long period of time. They also reflect the organizational knowledge about previous and potential course of action, expectations and what is truly needed to implement a new strategy or initiative.

Combining data and experience is preferable because it makes programs and activities stronger. However, when one is lacking, the other may have the potential to fill the gap. Thus, when program staff lack experience in priority-setting, surveillance data are needed to assess the local epidemic profile and the populations who are most at-risk for infection. When data are lacking, experience can help identify priority areas on which the program could begin to focus. Exploring the value of experience in decision-making, especially when data are lacking, is an important area for future research. Returning to Mexico to examine what program managers and staff identify as priority groups and comparing those assessments to local level data is one potential way to evaluate this idea.

I want to also outline additional areas for research and intervention that were generated through this research. Performing similar studies on data utilization on a national setting could compare the experience of *COESIDAs* and traditional state programs as well as compare Mexico's experiences to other middle-income countries. A follow-up study could also assess the changes in the decision space in state HIV/AIDS programs and their effects on overall program performance. In terms of interventions, local capacity and skills around data analysis for program implementation and advocacy are crucial. It is also important to define and implement strategic changes to the Mexican surveillance system and dissemination channels to encourage local data utilization.

All in all, even though data are a critical tool to driving improvements in health, they do not exist in a vacuum. In this research I explored all of the potential factors that can influence how data are used in decision-making, from politics to funding to data access. But it is also worth remembering that data and research need committed actors to be of any use. The following quotation from Carol Weiss summarizes it well,

> "There have been some substantial victories for policy-oriented research as well…But research does not win victories in the absence of committed policy advocates, savvy political work and happy contingencies of time, place and funds (p. 148)"[1]

My hope is that with this dissertation I have been able to shed light on the difficult and at times obscure process of decision-making and provide a clearer path for data to become part of it.

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APPENDIX: SURVEY INSTRUMENT

For researcher use ONLY. Do not complete

ID Number _____-_____

Exploring the Factors that Influence Surveillance Data Utilization in HIV/AIDS Programs in Mexico
SURVEY

Background
The purpose of this study is to explore different factors that might influence the use of HIV/AIDS surveillance data at the state program level. I will be using the information from this study to locate barriers to the use of surveillance data where its application could improve HIV/AIDS programming.

Information about the survey
Before starting the survey you will find a series of demographics questions. These will be used for analysis purposes only.

The main part of the survey has several sections. The first section will ask you some basic questions about your program's activities. The second section has questions relating to the characteristics of the surveillance data used in your program. Here you will also find questions relating more concretely to the data utilization process in your program. Next, there are questions about the resources available to your program. The last section focuses on the macro political factors that might influence the use of surveillance data in the program.

After completing the survey you will have the opportunity to provide comments about the questions that you have been asked. You will also be able to provide feedback about the structure of the survey and make comments about changes for the future.

Please answer all of these questions in the survey to the best of your ability and try to be as accurate as possible. I greatly appreciate any and all of your responses and feedback. Thank you again for agreeing to participate in this study.

Today's Date _____/_____/_____
DD MM YYYY

DEMOGRAPHICS

1. Gender Female Male Transgender

2. Date of birth _____/_____/_____
   DD MM YYYY

3. Highest level of education completed *(Check one ONLY please)*

☐ Less than high school
☐ High school diploma
☐ Bachelor's degree
☐ Master's degree
☐ Doctorate or professional degree (PhD, DrPH, JD, etc)
☐ Other, *please specify* _____

4. Primary employment title/Occupation:
   _____

5. Organization/Agency where you work *(eg. State HIV/AIDS program, CENSIDA, IMSS)*:
   _____

6. How long have you been working in this institution?
   _____ months _____ years

7. How long have you been working in HIV/AIDS-related work?
   _____ months _____ years

8. How long have you been working on HIV/AIDS at this institution?
   _____ months _____ years

9. Were you appointed, selected or elected to your position?
   ☐ Appointed
   ☐ Selected
   ☐ Elected

10. What are your primary responsibilities regarding HIV/AIDS?
    _____
    _____

11. Do you hold any other HIV-related positions not affiliated with this organization? If so, what are they?
    _____

NOTE: For purposes of this survey, please answer the questions in consideration of the job you consider your primary responsibility.

PROGRAM CHARACTERISTICS

The following questions relate to the HIV/AIDS program in your state. You will be asked questions about and at-risk populations in your state.

1. Which populations in your state are most at-risk for contracting HIV? *[Open-ended]*

   _____
   _____
   _____
   _____

2. What populations does your program work with regularly performing prevention activities? *[Check all that apply]*

   - ☐ Female sex workers
   - ☐ Male sex workers
   - ☐ Men who have sex with men (MSM)
   - ☐ Injecting drug users
   - ☐ Youth
   - ☐ Migrants
   - ☐ Transgender persons
   - ☐ Imprisoned populations
   - ☐ Indigenous populations
   - ☐ Women, not sex workers
   - ☐ Men, not MSM

3. What prevention activities does your program conduct with those populations? *[Open-ended]*

   _____
   _____
   _____
   _____

4. Who participates in the process to select populations that will receive prevention activities? *[Check all that apply]*

   - ☐ Program chief
   - ☐ Program staff
   - ☐ State Secretary of Health
   - ☐ CENSIDA
   - ☐ Other state health authorities: _____
   - ☐ Other: _____

5. Who makes the final decision on which populations will receive prevention activities? *[Open-ended]*

   _____
   _____
   _____
   _____

DATA CHARACTERISTICS

This section will cover four topics about surveillance data including: Data Collection and Quality, Relevance of Data at the Local Level, Availability and Accessibility of Data, the Local Capacity to Use Data and the Data Utilization Process.

Data Collection, Quality and Relevance at the Local Level

The following questions relate to the data collection process and activities for surveillance data in your state. You will be asked questions about data collection, indicator selection, the quality of the surveillance data that you and your program use and how relevant the surveillance data are to you and your program.

1. Which of the following statements reflects your program's participation in the **data collection process** for your state? *[Select only one response]*
    a. We develop the data collection plan and activities for our state and we implement them.
    b. We receive assistance from others to develop the data collection plan and activities for our state but we implement them ourselves.
    c. We conduct data collection activities but we do not receive help in developing the plan for our state.
    d. We do not participate in data collection activities.

2. Please indicate on the scale below the level of interest your program has in participating in **data collection** for your state. *[Select a number between 1 and 10 where 1 represents low interest and 10 represents high interest]*.

1	2	3	4	5	6	7	8	9	10
Low interest									High interest

3. What is the current approach to revising data collection methods? *[Select only one response]*
    a. Data collection methods can be and are revised as necessary.
    b. Data collection methods can be revised but it does not happen often.
    c. Data collection methods are very difficult to change.

4. Which of the following statements reflects your program's participation in the selection process for surveillance **data indicators** for your state? *[Select only one response]*
    a. Indicator selection is a collaborative process between program staff and federal authorities.
    b. We have input in indicator selection but our opinion does not weigh as much as others.

c. We have ideas about indicator selection but our opinion is not asked.
d. We do not participate in indicator selection.

5. Please indicate on the scale below the level of interest your program has in participating in **indicator selection** for your state. *[Select a number between 1 and 10 where 1 represents low interest and 10 represents high interest]*.

1	2	3	4	5	6	7	8	9	10
Low interest									High interest

6. What proportion of the current indicators is valuable to the program in some way? *[Select only one response]*

All of them Some of them A few of them None of them

7. What percent of the surveillance data that are collected are useful for prioritizing populations for prevention?

_____%

8. Which of the following statements reflects the relevance of indicators to program and planning needs? *[Select only one response]*
   a. Our current indicators reflect program and planning needs well.
   b. Some of our indicators reflect actual information needs for the program and planning.
   c. Very few of our indicators reflect actual information needs for the program and planning.
   d. None of our indicators are relevant to the program.

9. How adaptable are the data collection indicators? *[Select only one response]*
   a. We can adapt indicators if new needs are identified.
   b. Indicators can be changed but it is very hard to do.
   c. Indicators are never changed.

10. In the past, have you added indicators that were interesting to you to the data collection activities?
    ☐ No
    ☐ Yes → Which indicators did you add? When?

    _____

    _____

11. Which of the following statements reflects the current process for evaluating the surveillance system in your state? *[Select only one response]*
    a. Our surveillance system is evaluated regularly.
    b. Our surveillance system is evaluated but it is not done on a regular basis
    c. Our surveillance system is evaluated rarely.

12. When your surveillance system is evaluated, what happens with the results from the evaluation? *[Select only one response]*
    a. Any recommendations generated by the evaluation are implemented.
    b. We take any recommendations generated by the evaluation into consideration and sometimes we act on them if we can.
    c. We take any recommendations generated by the evaluation into consideration but we rarely act on them.
    d. We have no process to review and implement any recommendations generated by an evaluation.
    e. Our surveillance system has not been evaluated

INSTRUCTIONS: *We want to learn about your feelings about the collection, quality and relevance of surveillance data. Please indicate your level of agreement with these statements by selecting one of the options listed.*

13	Our data collection activities are set up only so we can meet our reporting guidelines.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
14	Our data collection activities often falls short of meeting our reporting guidelines.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
15	Indicators are reviewed on a regular basis to ensure they meet our program planning needs.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
16	Indicators could be dropped if they are no longer useful.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
17	Mechanisms and structures for monitoring and evaluation of the surveillance system exist within the organization.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
18	Data collection and analysis are conducted with fidelity to existing protocols.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
19	I do not put much faith in the quality of our data.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
20	The data we collect are necessary to prioritize populations for prevention.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
21	Our information needs are not reflected at all in our current indicators.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*

22. Which of the following statements reflects your view of the accuracy of surveillance data for your state? *[Select only one response]*
    a. I believe our surveillance data represent the actual epidemic profile of our state.
    b. I believe some of the data points in the surveillance data are accurate but others are not.
    c. I do not believe that our surveillance data accurately reflect the epidemic profile of our state.

23. How much is relevance to program and planning needs considered when indicators are selected? *[Select only one response]*
    a. We ensure that our indicators are relevant to our program and planning needs in some way.

b. We think about the relevance of indicators but it is not a requirement for indicator selection.
c. We do not take into account whether an indicator will provide relevant information when we select it.
d. We have no say in indicator selection so relevance does not matter.

Availability and Accessibility of Data

The following questions relate to the availability and accessibility of surveillance data that you and your program use or want to use. You will be asked questions about biological surveillance data, such as number of AIDS cases and HIV infections. You will also be asked questions about behavioral surveillance data, such as condom use with last sexual partner and exchanging sex for drugs or money.

1. Which ***biological*** surveillance data, such as AIDS cases or HIV infections, about your state are available to you? *[Open-ended]*

   _____
   _____
   _____

2. Which ***behavioral*** surveillance data, such as condom use among at-risk populations, about your state are available to you? *[Open-ended]*

   _____
   _____
   _____

3. How would you access surveillance data that you wanted when you are planning prevention activities? *[Open-ended]*

   _____
   _____
   _____

4. Do you know how to request surveillance data that your program needs? *[Select only one response]*
   a. I know how to request data and from whom.
   b. I know what data I want but I don't know how to get it.
   c. I don't know where or how to get any data that I don't have. → *SKIP to #7*

5. How difficult is it to request biological or behavioral data that you need for your program? *[Please circle one option for each type of surveillance data]*

Biological Data (eg. AIDS cases or HIV infections)	a. It is not difficult to request surveillance data we need.
	b. It can be difficult but not impossible to request data we need.
	c. It is very difficult to request data that we need.
Behavioral Data (eg. condom use or needle sharing)	a. It is not difficult to request surveillance data we need.
	b. It can be difficult but not impossible to request data we need.
	c. It is very difficult to request data that we need.

6. Once you have requested biological and behavioral surveillance data, how difficult are they to get? *[Please circle one option for each type of surveillance data]*

Biological Data (eg. AIDS cases or HIV infections)	a. We can get any data we want or ask for.
	b. We get some of the data we request.
	c. It is very difficult to get data we have requested.
Behavioral Data (eg. condom use or needle sharing)	a. We can get any data we want or ask for.
	b. We get some of the data we request.
	c. It is very difficult to get data we have requested.

7. Do you know how to find out what surveillance data are available to your program? *[Select only one response]*
   a. I know what data are available and I know who to ask if I have doubts.
   b. I don't what data are available but I know who to ask if I have doubts.
   c. I don't know how to find out what data are available to me or who to ask.

8. Where can you find ***biological*** surveillance data for your state? *[Check all that apply]*
   - ☐ Our own program records
   - ☐ CENSIDA website/system
   - ☐ SUIVE
   - ☐ SALVAR
   - ☐ Dirección General de Epidemiología website/system
   - ☐ State surveillance epidemiologist
   - ☐ National surveys
   - ☐ State surveys
   - ☐ Other: _____

9. Where can you find ***behavioral*** surveillance data for your state? *[Check all that apply]*
   - ☐ Our own program records
   - ☐ CENSIDA website/system
   - ☐ SUIVE
   - ☐ SALVAR
   - ☐ Dirección General de Epidemiología website/system
   - ☐ State surveillance epidemiologist
   - ☐ National surveys
   - ☐ State surveys

☐ Other: _____

INSTRUCTIONS: *We want to learn about your feelings about accessibility and availability of surveillance data utilization. Please indicate your level of agreement with these statements by selecting one of the options listed.*

10.	The data we have access to are hard to understand.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
11.	I do not try to access any more surveillance data beyond what is given to me.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
12.	Data are disaggregated in a way that our program can use for prevention planning.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*

13. The following chart asks about your awareness of and access to certain data points and indicators of surveillance data. Please be as complete as possible. *[Please complete each box]*

Data point / Indicator		**Aware of it?**	**Have it for your state?**		**Have access to national data?**		**Use it?**	**Want it?**	***Not Applicable for my State***
BIOLOGICAL DATA		**Yes / No**	**Yes / No / Don't Know**	**Most Current**	**Yes / No / Don't Know**	**Most Current**	**Yes / No**	**Yes / No**	
Eg.	***Cases of gonorrhea***	*Yes*	*Yes*	*2008*	*Yes*	*2005*	*No*	*Yes*	
1.	**New AIDS cases**								
2.	**Cumulative AIDS cases**								
3.	**New HIV infections**								
4.	**Cumulative HIV infections**								
5.	**Syphilis cases/infections**								
6.	**Other STIs**								
7.	**Mortality Rate**								
BEHAVIORAL DATA									
8.	**Female Sex Workers**								
9.	**Injecting Drug Users**								
10.	**Men who have Sex with other Men**								
11.	**Youth**								
12.	**Migrants**								
RESEARCH DATA									
13.	**Data/results**								

	from studies in your state								
PROGRAMMATIC DATA									
14.	**Condom distribution**								
15.	**Information and Education Campaigns**								
16.	**Workshops**								
17.	**Needle exchange**								

Local Capacity

The following questions relate to the capacity available at the local level in HIV/AIDS programs to use, analyze and interpret surveillance data.

1. What is the program's current capacity for using surveillance data to prioritize populations for prevention? *[Select only one response]*
    a. We have at least one staff member with special training who can use surveillance data to prioritize populations for prevention.
    b. We have at least one staff member who can use surveillance data to prioritize populations for prevention but s/he has no special training in this area.
    c. We have access to a staff member who can use surveillance data to prioritize populations for prevention.
    d. We share a staff member with another program/unit who can use surveillance data to prioritize populations for prevention.
    e. We do not have any staff members who can who can use surveillance data to prioritize populations for prevention.

2. Which of these statements best reflects your program's experience with using surveillance data to adapt prevention initiatives sent down from the federal level to reflect the local epidemic profile? *[Select only one response]*
    a. We usually use our own surveillance data to adapt any prevention initiatives that are sent down from the federal level.
    b. We have used our own surveillance data to adapt prevention initiatives but we do not do it all the time.
    c. We have used our own surveillance data to adapt prevention initiatives but it was not successful.
    d. We do not use our own surveillance data to adapt any prevention initiatives that are sent down from the federal level.

3. How capable do you feel to use surveillance data to set priorities for the program? *[Select a number between 1 and 10 where 1 represents low capacity and 10 represents high capacity]*.

   1 2 3 4 5 6 7 8 9 10
   Low capacity High capacity

4. What proportion of the staff in the program can conduct cost-effectiveness analyses?

   _____ %

5. How often are trainings/workshops offered in surveillance data utilization? *[Select only one response]*

   Frequently Sometimes Hardly ever Never

   ☐ I don't know how often trainings/workshops are offered.

6. Have you ever participated in a training/workshop for surveillance data utilization?
   ☐ No
   ☐ Yes → How many trainings have you participated in? What topics were covered? Which organization offered the trainings?
   _____
   _____
   _____

INSTRUCTIONS: *We want to learn about your feelings about local capacity in your program. Please indicate your level of agreement with these statements by selecting one of the options listed.*

7.	I see no value of using data to set priorities.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
8.	I have the authority to use surveillance data to set priorities for the program.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
9.	How successful has the program been in the past in adapting national initiatives to the local context?	*Very Successful*	*Successful*	*Unsuccessful*	*Very Unsuccessful*

Data Utilization Process

This section includes questions that relate specifically to the process of using surveillance data to plan program strategies and to prioritize populations for prevention.

1. How often do you use surveillance data when setting priorities for your program?

   Always Sometimes Rarely Never

2. Are **biological** surveillance data, such as number of AIDS cases, utilized during the planning process to prioritize populations for prevention? *[Select only one response]*
   - ☐ Yes
   - ☐ No
   - ☐ I don't know

3. Are **behavioral** surveillance data, such as condom use for an at-risk population, utilized during the planning process to prioritize populations for prevention? *[Select only one response]*
   - ☐ Yes
   - ☐ No
   - ☐ I don't know

4. When we plan our program activities,
   a. …we regularly integrate surveillance data to identify which populations to target.
   b. …we consult/review surveillance data to identify which populations to target.
   c. …we do not use surveillance data to identify which populations to target.

5. When we plan our program strategy,
   a. …we regularly integrate surveillance data into our planning process.
   b. …we consult/review surveillance data in our planning process.
   c. …we do not use surveillance data in our planning process.

INSTRUCTIONS: *We want to learn about your feelings about surveillance data utilization and program planning. Please indicate your level of agreement with these statements by selecting one of the options listed.*

I believe using surveillance data to identify populations we should target for prevention…					
6.	…improves the program.	*Strongly Agree (1)*	*Agree (1-2)*	*Disagree (2-3)*	*Strongly Disagree (3)*
7.	… helps us reach the people who need the activities the most.	*Strongly Agree (1)*	*Agree (1)*	*Disagree (2-3)*	*Strongly Disagree (3)*
8.	…is useless.	*Strongly Agree (3)*	*Agree (3)*	*Disagree (2)*	*Strongly Disagree (1)*
9.	…is something we should do on a regular basis.	*Strongly Agree (1)*	*Agree (1-2)*	*Disagree (2-3)*	*Strongly Disagree (3)*
These are general statements about surveillance data utilization in your program					
10	I believe our program has all of the <u>necessary</u> tools to incorporate surveillance data into our	*Strongly Agree*	*Agree (1-2)*	*Disagree (2-3)*	*Strongly Disagree*

	program planning.	*(1-2)*			*(3)*
11	I believe our program has the <u>right</u> tools to incorporate surveillance data into our program planning.	*Strongly Agree (1)*	*Agree (1-2)*	*Disagree (2)*	*Strongly Disagree (3)*
12	I believe that people in my position in our program can contribute to surveillance data utilization.	*Strongly Agree (1)*	*Agree (1-2)*	*Disagree (2)*	*Strongly Disagree (3)*

13. Is there anyone who objects to using surveillance data when prioritizing populations for prevention?
    - ☐ No
    - ☐ Yes → How do his/her objections influence the process for prioritizing populations for prevention?

      _____
      _____

14. Describe how surveillance data are currently incorporated into the planning process to prioritize populations for prevention.

    _____
    _____
    _____
    _____

    14a. How could this process be improved in the future?

    _____
    _____
    _____
    _____

RESOURCES

The next section will cover resource issues facing your HIV/AIDS program at the state level. You will be asked questions about financial, human, technological and material resources. Technological resources include computers, software and hardware, network access (intranet and internet). Material resources include materials for program activities, and space and infrastructure allocated to the program.

NOTE: *For the purposes of this section designated functions include data collection and analysis, program planning, program and activity implementation, policy development and advocacy.*

1. What is your program's current resource situation in regards to its designated functions? *[Please select one response for each resource category]*

Financial Resources	a. Our program has funding for all its functions.
	b. Our program has enough funding to perform all of its functions but not well.
	c. Our program has the funding to cover some of its functions but not all of them.
	d. Our program does not have enough funding to cover even its basic functions.
Human Resources	a. Our program has personnel for all its functions.
	b. Our program has enough personnel to cover all of it functions but not well.
	c. Our program has enough personnel to cover some of its functions but not all of them.
	d. Our program does not have enough personnel to cover even its basic functions.
Technological Resources (eg. computer, software)	a. Our program has technological resources for all its functions.
	b. Our program has enough technological resources to cover all of it functions but not well.
	c. Our program has enough technological resources to cover some of its functions but not all of them.
	d. Our program does not have enough technological resources to cover even its basic functions.
Material Resources (eg. materials for activities, infrastructure)	a. Our program has material resources for all its functions.
	b. Our program has enough material resources to cover all of it functions but not well.
	c. Our program has enough material resources to covers some of its functions but not all of them.

	d. Our program does not have enough material resources to cover even its basic functions.

2. Is it possible to access extra resources for additional activities? *[Please select one response for each resource category]*

Financial Resources	a. Yes, we can access extra funds for additional activities if we need them.
	b. Yes, we have access to additional funding but it is hard to get.
	c. No, we cannot access additional funding whether we need it or not.
Human Resources	a. Yes, we can recruit or hire additional staff members if we need them.
	b. Yes, we can recruit or hire additional staff members but only on a temporary basis
	c. Yes, we can recruit or hire additional staff members but they are hard to get.
	d. No, we cannot recruit or hire additional staff members.
Technological Resources (eg. computer, software)	a. Yes, we can access additional technological resources if we need them.
	b. Yes, we can access additional technological resources but they are hard to get.
	c. No, we cannot access additional technological resources.
Material Resources (eg. materials for activities, infrastructure)	a. Yes, we can access additional material resources if we need them.
	b. Yes, we can access additional material resources but they are hard to get.
	c. No, we cannot access additional material resources.

INSTRUCTIONS: *We want to learn about your feelings about how resources affect program planning. Please indicate your level of agreement with these statements by selecting one of the options listed.*

Financial Resources					
3.	Financial resources are allocated according to the priorities set during program planning.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
4.	Current funding can be used flexibly to support effective programs and activities.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
5.	We have funding for all of the activities we want to do.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
6.	We have the freedom to allocate funds according to program needs.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
7.	Our program has enough financial resources that we are able to go beyond what we "have to do" and are able to pursue program goals that we set for ourselves.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*

8.	Our program experiences regular delays in disbursement of funds.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
9.	The quality of our program is compromised by lack of funding.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
10.	Budgeting, or where money gets allocated, does not change very much from year to year.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
11.	Only prevention activities that are acceptable to the local community can get funded.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
Human Resources					
12.	Personnel are allocated according to the priorities set during program planning.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
13.	Current staff can be used flexibly to support effective programs and activities.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
14.	If I could switch out of the HIV/AIDS program to another program in my organization (SSA, IMSS, ISSSTE, state government), I would.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
Technological Resources					
15.	Technological resources are allocated according to the priorities set during program planning.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
16.	Current technological resources can be used flexibly to support effective programs and activities.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
17.	Network access within my organization is not a problem for our program.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
18.	It is easy to get additional technological support if we need it.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
Material Resources					
19.	Material resources are allocated according to the priorities set during program planning.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
20.	Current material resources can be used flexibly to support effective programs and activities.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
21.	If we need infrastructure improvements, we can get them easily.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*

Financial Resources

22. How is the yearly budget process for the program conducted? *[Open-ended]*

_____

_____

_____

_____

23. Has a budget for the program ever not been approved?
    - ☐ No
    - ☐ Yes → Please explain.

_____

_____

_____

24. What role do financial considerations play when you are planning the program's prevention activities? *[Select only one response]*
    a. Financial resources are not a consideration in our program planning.
    b. We take finances into consideration when we are planning activities but it is not our primary concern.
    c. We take finances into consideration when we are planning activities.
    d. Finances are our primary concern when we are planning activities.

25. Does your program designate financial resources specifically for analyzing surveillance data when you are prioritizing populations for prevention? *[Select only one response]*
    a. My program has resources specifically designated for analyzing surveillance data during program planning and they are enough.
    b. My program does not have enough resources to designate for analyzing surveillance data.
    c. My program does not designate resources for analyzing surveillance data.

Human Resources

26. How is program staff distributed in your state? *[Select only one response]*
    a. Program staff is distributed throughout the state.
    b. Program staff is not distributed across the state but they can be mobilized if needed.
    c. Program staff is only deployed across the state for specific activities.
    d. Program staff is located in the capital and rarely ventures out to the rest of the state.

27. How do services in other parts of the state compare to those in the capital city? *[Select only one response]*
    a. Services in the interior are just as good as or better than those in the capital city.
    b. Services in the interior are not as good than in the capital city but not significantly so.
    c. Services in the interior are much worse than those in the capital city.

28. Personnel turnover is…
    a. …not a big problem in our program.
    b. …used to be a big problem in our program but isn't anymore.
    c. …is a big problem in our program.

29. What do other programs in your organization think about the human resources dedicated to the HIV/AIDS program? *[Open-ended]*

_____

_____

Technological and Material Resources, such as computers, software, materials for activities, and infrastructure.

30. Does your program have a computer for data collection and analysis? *[Select only one response]*
    a. Our program has a dedicated computer(s) for data collection and analysis.
    b. Our program shares a computer with other programs.
    c. Our program has access to a computer but access is infrequent.
    d. Our program does not have access to a computer.

31. Which of these statements best describes the current status of the computer software your program uses to collect and analyze surveillance data? *[Select only one response]*
    a. Our software is frequently updated.
    b. Our program has good software but it needs to be updated.
    c. Our software is outdated.

32. Which of these statements best describes the current status of your program's infrastructure? *[Select only one response]*
    a. Our program's infrastructure is in good shape.
    b. Our program's infrastructure is outdated but we work around it.
    c. Our program's infrastructure is non-functional.

33. Have you (or anyone you know in the program) ever fixed program materials (eg. technological, infrastructure) yourself or at your expense?
    ☐ No
    ☐ Yes → What was fixed? Why did you fix it/have it fixed yourself?

    _____
    _____
    _____

MACRO POLITICAL/POLICY

This last section will cover macro political issues facing the HIV/AIDS program. There are four sub-sections in this portion: Communications, Organizational Behavior, Policy Environment and Decision-Making Power.

Communications

The following questions relate to the communication channels and methods used to distribute surveillance data and related information to state HIV/AIDS programs.

1. Which of the following statements reflects the current situation regarding distribution of surveillance data and related information to the state HIV/AIDS programs? *[Select only one response]*
    a. Surveillance data are distributed to all state programs regularly.
    b. Surveillance data are supposed to be distributed to all state programs regularly but they are often late.
    c. Surveillance data are distributed to some state programs regularly but not to others.
    d. Surveillance data are supposed to be distributed to all state programs but that happens rarely.
    e. There is no process for distributing surveillance data to all the state programs.

2. How often are surveillance data and related information distributed to the state HIV/AIDS programs? *[Select only one response]*
    a. Daily
    b. Weekly
    c. Monthly
    d. Every 3 months
    e. Every 6 months
    f. Yearly

3. Which of the following statements reflects how surveillance data dissemination is affected by changes in personnel at the state program? *[Select only one response]*
    a. Surveillance data reach the program regardless of staffing issues or personnel turnover at the program.
    b. Surveillance data can be held up if they are sent to the wrong person.

4. Which of the following statements reflects the current process at your organization (SSA, IMSS, ISSSTE, state government) for disseminating surveillance data and related information on **an emergency basis** to the state HIV/AIDS programs? *[Select only one response]*
    a. My organization has a process for distributing data during an emergency which works well.

b. My organization has a process for distributing data during an emergency and it works better than the process for regular dissemination.
c. My organization has a process for distributing data during an emergency but it is difficult to use.
d. My organization has a process for distributing data during an emergency but it is inefficient.
e. My organization has a process for distributing data during an emergency but I do not know what it is.
f. My organization does not have a process for distributing data during an emergency.

5. Please indicate on the scale below your impressions about the current format that is used when surveillance data are distributed in **printed materials**. *[Select a number between 1 and 10 where 1 represents low and 10 represents high].*

1 Hard to Understand	2	3	4	5	6	7	8	9	10 Understandable
1 Hard to Use	2	3	4	5	6	7	8	9	10 User-friendly
1 Useless	2	3	4	5	6	7	8	9	10 Useful

☐ I have never seen surveillance data distributed through printed materials.

6. Please indicate on the scale below your impressions about the current format that is used when surveillance data are distributed **online**. *[Select a number between 1 and 10 where 1 represents low and 10 represents high].*

1 Hard to Understand	2	3	4	5	6	7	8	9	10 Understandable
1 Hard to Use	2	3	4	5	6	7	8	9	10 User-friendly
1 Useless	2	3	4	5	6	7	8	9	10 Useful

☐ I have never seen surveillance data distributed online.

7. Please check all the communication channels that you recognize for the dissemination of surveillance data and related information. *[Check all that apply]*

☐ Email directly to you
☐ Email listserv, such as epidestatales@...
☐ Printed materials (eg. report)
☐ CENSIDA's website

- ☐ Organizational website (SSA, IMSS, ISSSTE, state government)
- ☐ Organization's server
- ☐ Other: _____

8. Please check all the communication channels that you have personally used to **send** surveillance data and related information to others in the last 6 months. *[Check all that apply]*
   - ☐ Email directly to you
   - ☐ Email listserv, such as epidestatales@...
   - ☐ Printed materials (eg. report)
   - ☐ CENSIDA's website
   - ☐ Organizational website (SSA, IMSS, ISSSTE, state government)
   - ☐ Organization's server
   - ☐ Other: _____

9. Please check all the communication channels that you have personally used to **receive** surveillance data and related information from others in the last 6 months. *[Check all that apply]*
   - ☐ Email directly to you
   - ☐ Email listserv, such as epidestatales@...
   - ☐ Printed materials (eg. report)
   - ☐ CENSIDA's website
   - ☐ Organizational website (SSA, IMSS, ISSSTE, state government)
   - ☐ Organization's server
   - ☐ Other: _____

10. Which of these communication channels would you prefer for receiving data and information? *[Please mark your top 3 choices regardless of whether you are aware of them or have used them before]*.
    - ☐ Email directly to you
    - ☐ Email listserv, such as epidestatales@...
    - ☐ Printed materials (eg. report)
    - ☐ CENSIDA's website
    - ☐ Organizational (SSA, IMSS, ISSSTE, state government) website
    - ☐ Organization's server
    - ☐ Other: _____

INSTRUCTIONS: *We want to learn your feelings about how you access surveillance data. Please indicate your level of agreement with these statements by selecting one of the options listed.*					
11	I can get surveillance data from multiple sources.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
12	I cannot access the current distribution channels for surveillance data.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*

Organizational Behavior

The following questions relate to the organizational behavior of your organization. For the purposes of this section, please focus on your organization whether it is SSA, IMSS, ISSSTE or the state government. Please consider both the structure and culture of your organization when you answer these questions.

1. Which of these statements most closely reflects your organization's (SSA, IMSS, ISSSTE, state government) current investment **of manpower** towards surveillance data utilization for priority-setting? *[Select only one response]*
    a. My organization gives us the necessary manpower to use surveillance data for priority-setting.
    b. My organization gives us manpower to use surveillance data for priority-setting but it's not enough.
    c. My organization gives us manpower to use surveillance data for priority-setting but it's not the right kind of help.
    d. My organization does not direct any manpower specifically for using surveillance data for priority-setting.

2. Which of these statements most closely reflects your organization's (SSA, IMSS, ISSSTE, state government) current investment **of training** towards surveillance data utilization for priority-setting? *[Select only one response]*
    a. My organization gives us the necessary training to use surveillance data for priority-setting.
    b. My organization gives us training to use surveillance data for priority-setting but it's not enough.
    c. My organization gives us training to use surveillance data for priority-setting but it's not the right kind of training.
    d. My organization does not direct any training specifically towards using surveillance data for priority-setting.

3. Has your organization (SSA, IMSS, ISSSTE, state government) conducted any activities to promote surveillance data utilization in the last year?
    ☐ No
    ☐ Yes → What activities were conducted? How many were there in the last year?
    _____
    _____
    _____

4. Does your organization (SSA, IMSS, ISSSTE, state government) show interest in your process for prioritizing populations for prevention? *[Select only one response]*
    a. My organization is interested in how we set priorities for the program and they evaluate whether we have used our surveillance data in our decisions.
    b. My organization is interested in how we set priorities for the program but their reviews are infrequent or incomplete.

c. My organization is interested in how we set priorities for the program but they have no way of checking whether we used surveillance data to develop them.
d. My organization has little interest in how we set priorities for the program.

5. Think about your organization (SSA, IMSS, ISSSTE, state government), does it expect you to use surveillance data in your program planning? *[Select only one response]*
    a. Yes, my organization does expect data utilization and we receive support or assistance from them in this area.
    b. Yes, my organization does expect us to use surveillance data but we receive little support or assistance from them in this area.
    c. No, my organization does not expect us to use surveillance data.

INSTRUCTIONS: *We want to learn about your feelings about surveillance data utilization in your organization (SSA, IMSS, ISSSTE, state government). Please indicate your level of agreement with these statements by selecting one of the options listed.*

6.	I feel that my organization's leadership promotes surveillance data utilization.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
7.	I feel that CENSIDA's leadership promotes surveillance data utilization.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
8.	I feel that my program's leadership promotes surveillance data utilization.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
9.	It is clear to me what my organization expects of my program in terms of surveillance data utilization.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
10.	My organization gives us the time we need to use surveillance data to prioritize populations for prevention.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
11.	The HIV/AIDS program is placed high in the state government structure.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
12.	The HIV/AIDS program chief reports to an influential superior officer at CENSIDA (IMSS, ISSSTE, state government).	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
13.	The program chief reports to an influential superior officer at the state government.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*

14. Which of the following statements most closely resembles the situation in your program regarding goals and strategies for prevention? *[Select only one response]*
    a. Formal program goals for prevention exist and there are specific and realistic strategies to meet them.
    b. Formal program goals for prevention exist but the strategies to meet them are not appropriate.
    c. Formal program goals for prevention exist but there are no strategies to meet them.
    d. Formal program goals for prevention do not exist.

15. Does your supervisor(s) ever express to you an expectation that surveillance data should be used to prioritize populations for prevention? *[Select only one response]*
    a. My supervisor expects me to use surveillance data to prioritize populations and s/he checks my work to ensure that I do.
    b. My supervisor expects me to use surveillance data to prioritize populations but s/he doesn't check my work to see if I did.
    c. My supervisor expects me to use surveillance data to prioritize populations but s/he has no way of checking my work to see if I did.
    d. My supervisor has never expressed an expectation that I use surveillance data when setting priorities.

16. Which of the following do you think expect you to use surveillance data in priority-setting for the program? *[Check all that apply]*
    - ☐ My supervisor
    - ☐ My colleagues
    - ☐ My organization's leadership (SSA, IMSS, ISSSTE, state government)
    - ☐ Program leadership
    - ☐ CENSIDA leadership
    - ☐ Other: _____

Policy Environment

The following questions relate to the policy environment in which the state HIV/AIDS programs operate. Sometimes, elected officials and community leaders worry about collecting or publicly releasing data about the HIV/AIDS epidemic because of concerns that a clear picture of who is affected might offend certain segments of society. This section will try to capture some of those concerns and how they affect the state HIV/AIDS program.

1. Are there any laws that limit the kinds of interventions the program can implement, such as prohibit interventions like needle exchange? *[Select only one response]*
    a. There are no laws now that limit the work the program can do.
    b. There are no laws now that limit the work the program can do but those laws used to exist.
    c. There are no laws now that limit the work the program can do but lawmakers have threatened to enact one (or some).
    d. There are laws now that limit the work the program can do.

2. Does the local/state government expect you to use surveillance data to prioritize populations for prevention? *[Select only one response]*
    a. Yes, the local/state government expects us to use surveillance data.

b. Yes, the local/state government expects us to use surveillance data but they don't mean it.
c. No, the local/state government does not expect us to use surveillance data.

INSTRUCTIONS: *We want to learn about your feelings about the policy environment in which your program operates. Please indicate your level of agreement with these statements by selecting one of the options listed.*

3.	There is awareness among policy makers that conducting activities with vulnerable populations, such as sex workers and injecting drug users, is important to AIDS prevention.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
4.	We set priorities for which populations we are going to work with based on what is acceptable to the local community.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
5.	We set priorities for which populations we are going to work with based on political pressures from the local government.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
6.	We set priorities for which populations we are going to work with based on local politics.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
7.	The local/state government threatens our resources (i.e. the program's budget) to get the program to do what it wants.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
8.	The program experiences different pressures depending on which political parties are in power (eg. liberal vs. conservative).	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
9.	How supportive is the current policy environment of using surveillance data for program planning?	*Very Supportive*	*Somewhat Supportive*	*Somewhat Unsupportive*	*Very Unsupportive*
10.	How supportive is the local/state government of using surveillance data for program planning?	*Very Supportive*	*Somewhat Supportive*	*Somewhat Unsupportive*	*Very Unsupportive*

11. Does your program experience pressure from outside actors **not** to collect certain types of data regarding the HIV/AIDS epidemic?
    - ☐ No
    - ☐ Yes → Who are they and what do they not want collected?

    _____

    _____

12. Which of these statements apply to the local community's views on the program's activities? *[Please check all that apply]*
    - ☐ The local community does not know much/does not care about the program's activities.
    - ☐ The local community views the program's activities favorably.
    - ☐ The local community does not approve of the program activities.
    - ☐ The local community has tried to stop program activities in the past but has not succeeded.
    - ☐ The local community has tried to stop program activities in the past and has succeeded.

13. Which of these statements apply to the local community's views on the program's target populations? *[Please check all that apply]*
    - ☐ The local community does not know much/does not care about the program's target populations.
    - ☐ The local community approves of the program's target populations.
    - ☐ The local community does not approve of the program working with socially undesirable groups (sex workers, injecting drug users).
    - ☐ The local community does not want the program working with socially undesirable groups (sex workers, injecting drug users).

14. Are there any key organized groups that have an interest in how the program prioritizes populations for prevention?
    - ☐ No
    - ☐ Yes → Who are these groups?

      _____

      _____

Decision-Making Power

The following questions relate to the decision-making power around the HIV/AIDS program and its activities.

1. Please indicate your perception about the level of influence each of these actors has on the priority-setting process for the program:

	High	**Medium**	**Low**	***Not Applicable***
Program staff				
Program chief				
The State Secretary of Health				
Somebody at CENSIDA				

Another state health authority: _____				
Other: _____				

2. Where does the final decision-making power for prioritizing populations for prevention currently reside? *[Select only one response]*
    a. With the program chief
    b. With another staff position: _____
    c. With another program staff member: _____
    d. With someone outside of the program: _____
    e. With someone at CENSIDA

3. In what areas do you believe the program chief has the final decision-making power? *[Open-ended]*

    _____
    _____
    _____
    _____

4. Have program activities ever been changed by someone outside the program?
    ☐ No
    ☐ Yes → Please explain.

    _____
    _____
    _____

5. How many times in the last 5 years has there been a new program chief?

    Number of times: _____

INSTRUCTIONS: *We want to learn about your feelings about decision-making power in your program. Please indicate your level of agreement with these statements by selecting one of the options listed.*

6.	The program has the complete decision-making power to make and carry out decisions about which populations to target for prevention.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
7.	If someone else were in the position of program chief, the HIV/AIDS program would have less power over how decisions get made.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*
8.	Our program cannot suggest working with certain populations, such as sex workers or injecting drug users, because persons in power are against it or have been against it in the past.	*Strongly Agree*	*Agree*	*Disagree*	*Strongly Disagree*

Thank you very much for your participation in this survey. Your answers will help in the collection of information regarding the issues that are faced by state HIV/AIDS programs.