# HOW CAN HIV CARE TRANSITION BE IMPROVED WHEN U.S. IMMIGRATION AND CUSTOMS ENFORCEMENT REPATRIATES DETAINED ALIENS TO MEXICO?

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A dissertation submitted to the faculty at the University of North Carolina at Chapel Hill in partial fulfillment of the requirements for the degree of Doctor of Public Health in the Department of Health Policy and Management in the Gillings School of Global Public Health.

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#### **ABSTRACT**

Alyson Rose-Wood: How Can HIV Care Transition Be Improved When U.S. Immigration and Customs Enforcement Repatriates Detained Aliens to Mexico?

(Under the direction of Sandra Greene)

Given the seriousness of HIV infection, the clinical implications of interrupted antiviral therapy, and the availability of free HIV treatment in Mexico, continuity of care for HIV-infected aliens detained by U.S. Immigration and Customs Enforcement (ICE) who are repatriated to Mexico is important. While ICE provides opt-in HIV screening and treatment for aliens during detention, a major gap exists in the care transition for HIV-infected detainees once they are repatriated from the United States.

A convergent mixed-methods design was used to address how care transition of HIV-infected aliens repatriated to Mexico could be improved. The number of HIV-infected aliens repatriated to Mexico annually was estimated using data on HIV prevalence rates among aliens in ICE detention from the Texas Department of State Health Services. U.S.-based key informants were interviewed about HIV care transition and the factors facilitating or hindering its success. Bardach's eightfold path was used to identify policy solution(s). Kingdon's multiple streams model was used to develop policy advocacy recommendations to take advantage of "windows of opportunity" to reach identified policy goals.

Secondary data analysis found that while likely an underestimate, every two weeks ICE is repatriating 2-3 (avg) HIV-infected aliens to Mexico. Ways to improve care transition suggested by key informants included ensuring that U.S. and Mexican health authorities are included in the removal of HIV-infected aliens in ICE custody and addressing three challenges for binational

HIV medical record sharing (access, confidentiality, and patient consent). The policy analysis found that the most impactful long-term option for improving HIV care transition is to develop a binational continuity of care program that includes a platform for sharing medical information. A short-term step is to ensure implementation of extant ICE standards for HIV care transition. The multiple streams model suggested possible avenues to promote program implementation such as engaging with advisory committees that advise the U.S. government on HIV care.

The most impactful option for improving HIV care transition is the development of a binational platform for sharing of HIV data and medical records. Opportunities to move this policy onto the formal government agendas need to be sought.

For Peter for walking beside me.

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#### LIST OF ABBREVIATIONS

ACET Advisory Committee for the Elimination of Tuberculosis

ADHS Arizona Department of Health Services

AIDS Acquired Immunodeficiency Syndrome

ARV Antiretroviral

BIDS Binational Border Infectious Disease Surveillance Program

CAPASITS Centro Ambulatorio de Prevención y Atención en SIDA

CBP U.S. Customs and Border Protection

CDC Centers for Disease Control and Prevention

CureTB Program Linking People with TB to Care as They Move from the United States

DHS Department of Homeland Security

DOI Diffusion of Innovation Policy Analysis Framework

ECHO Extension for Community Health care Outcomes

EO Executive Order

ERO Enforcement and Removal Operations

FY Fiscal Year

GAO Government Accountability Office

HIV Human Immunodeficiency Virus

IAD Institutional Analysis and Development Policy Analysis Framework

ICE U.S. Immigration and Customs Enforcement

IHSC ICE Health Service Corps

IIRIRA Illegal Immigration Reform and Immigrant Responsibility Act

INA Immigration and Nationality Act

INS U.S. Immigration and Naturalization Service

INSABI El Instituto Nacional de Salud para el Bienestar (The National Institute of Health

or Well-being)

IRB Institutional Review Board

MDR Multi-Drug Resistant

MEDSIS Medical Electronic Disease Surveillance System

MSF Multiple Streams Framework for Policy Analysis

NDS National Detention Standards

OIG Office of the Inspector General

PBNDS Performance-Based Detention Standards

PHSP Public Health, Safety, and Preparedness Unit

RCA Risk Classification Assessment

SIDA Sindrome de Inmunodeficiencia Adquirida (AIDS in Spanish)

TB Tuberculosis

TB Net Multi-National Tuberculosis Patient Tracking and Referral Program

United States United States of America

USCIS U.S. Citizenship and Immigration Services

USMBHC U.S.-México Border Health Commission

WHO World Health Organization

XDR Extensively Drug Resistant

## **CHAPTER 1: INTRODUCTION**

## **Statement of the Issue**

The Immigration and Nationality Act (INA) (INA, 1952) contains many of the most important provisions of U.S. immigration law amended over the years. The last significant INA amendment occurred in 1996 with the enactment of the Illegal Immigration Reform and Immigrant Responsibility Act, or IIRIRA (IIRIRA,1996). IIRIRA changes to the INA included mandating the placement of every illegal alien convicted of an aggravated felony in expedited removal proceedings. As a result, the number of aliens held in immigration detention in the United States of America (United States) has grown significantly between 1996 and 2020.

In fiscal year (FY) 2019, the average daily population of illegal aliens maintained in adult or family U.S. detention facilities was 50,165 (U.S. Immigration and Customs Enforcement Agency [ICE], 2019). This total was across more than 225 facilities, mostly state and county jails, but also corporate detention centers and 23 facilities run by ICE (U.S. Department of Homeland Security [DHS], 2019). Aliens are incarcerated while awaiting judicial or legal proceedings or transportation to their country of citizenship.

ICE manages health-care provision for adults (18 years or older) and families in immigration detention centers. Despite the wide variety of physical settings, each detention facility contains a medical unit where detainees receive medical care under a common set of administrative ICE rules (ICE Health Service Corps [IHSC], 2019). According to ICE guidance, detainees should receive a health intake screening within 12 hours of arrival as well as a

comprehensive health assessment within two weeks of detention (ICE, 2011, 2019). In FY 2019, the average length of detention in ICE facilities was just under eight weeks (54.5 days) (ICE, 2019). The INA instructs DHS to detain aliens ordered to be removed and to remove them from the United States within 90 days. However, no statutory limitation exists on the amount of time DHS may detain an alien while removal proceedings are pending.

According to DHS, since 2001, the United States has removed more than 4.5 million aliens, primarily of Mexican origin (DHS, 2019). In FY 2019, 48% of all aliens removed by ICE were from Mexico (ICE, 2019). Table 1 presents the total number of aliens removed in FY 2018 and FY 2019 across the top four countries of citizenship.

Table 1. Aliens Removed by ICE, Top Four Countries of Citizenship (FY 2018, 2019)

	Country	FY 2018: Total # of removed aliens (% of total)	FY 2019: Total # of removed aliens (% of total)
	Mexico	141,045 (55%)	127,492 (48%)
4	Guatemala	50,390 (20%)	54,919 (21%)
4	Honduras	28,894 (11%)	41,800 (16%)
4	El Salvador	15,445 (6%)	18,981 (7%)

Source: U.S. Immigration and Customs Enforcement, FY 2019 Enforcement and Removal Operations Report.

Most aliens removed by ICE to Mexico are transferred to land border crossings located along the U.S.-Mexico border. It is the U.S. government's responsibility to get them to a drop off point but not their final destination (DHS, 2019). Removed aliens are typically released into the general community of these border crossings with little to no support or resources. DHS statistics show that removal from the United States, particularly for those aliens repatriated to Mexico,

does not mean that the alien will never again be a member of a U.S. community. In FY 2019, U.S. Custom and Border Patrol's (CBP) Office of Border Patrol reported that 7% of individuals were apprehended more than one time by CBP within the same year (CBP, 2019). Out of the 188,382 criminal aliens removed by ICE in 2011, at least 86,699, or 46%, had been repatriated earlier and had illegally returned to the United States (ICE, 2019). Once a removed alien completes an illegal U.S. reentry, in nearly all cases, the alien will go undetected unless charged with another crime or if the alien is recognized by local law enforcement officials. Thus, the number of aliens who make an illegal reentry is higher than DHS data indicate.

# Transition in Responsibility for Enforcing the INA

Before March 1, 2003, the responsibility for enforcing the INA belonged solely to the Immigration and Naturalization Service (INS). The INS was an agency within the Department of Justice, and ultimate legal authority under the INA, residing in the attorney general's office. The CBP, although often referred to as an independent entity, was a division of the INS.

With the creation of DHS on March 1, 2003, authority over the INA was transferred to the Secretary of Homeland Security (Homeland Security Act, 2002). DHS split the INS into three agencies: U.S. Immigration and Customs Enforcement (ICE), U.S Customs and Border Protection (CBP), and U.S. Citizenship and Immigration Services (USCIS). All three agencies now share responsibility for enforcing the INA. USCIS does not arrest aliens, but it puts aliens into removal proceedings. Although both ICE and CBP arrest aliens, ICE is solely responsible for detaining aliens during the removal process. CBP does not detain aliens beyond the time spent at the processing station. If CBP decides to detain an alien, then that alien is turned over to ICE for further action. ICE is the agency primarily responsible for immigration enforcement

efforts in the interior of the United States. The Health Service Corps (IHSC), a division within ICE, provides health oversight for detainees.

# **Current Immigration Enforcement Policies**

On January 25, 2017, President Donald J. Trump issued Executive Order (EO) 13768, Enhancing Public Safety in the Interior of the United States, which set forth the Administration's immigration enforcement and removal priorities (Office of the Press Secretary, 2017). DHS' February 20, 2017, implementation memorandum, Enforcement of the Immigration Laws to Serve the National Interest, provided further direction for implementing policies set forth in the EO (DHS, 2017). Together, the EO and implementation memorandum expanded ICE's enforcement focus to include removable aliens who: 1) have been convicted of a criminal offense; 2) have been charged with a criminal offense that has not been resolved; 3) have committed acts which constitute a chargeable criminal offense; 4) have engaged in fraud or willful misrepresentation in connection with any official matter before a governmental agency; 5) have abused any program related to receipt of public benefits; 6) are subject to a final order of removal but have not complied with their legal obligation to depart the United States; or 7) in the judgment of an immigration officer, otherwise pose a risk to public safety or national security.

#### ICE Health Care

ICE is responsible for providing medical care to all aliens in its custody and pays all health care costs for detained aliens (IHSC, 2019). According to ICE guidance, detainees should receive a health intake screening upon arrival as well as a comprehensive health examination conducted by a health care practitioner within 14 days of arrival (ICE, 2011, 2019). This comprehensive assessment includes both physical and mental health screenings. Detention

facilities are not required to provide assessments to any detainee who has had a documented comprehensive health assessment conducted by ICE within the last 90 days.

IHSC provides direct on-site patient care to those aliens in dedicated ICE detention facilities (note: this does not include facilities with which ICE has intergovernmental service agreements, such as state and local law enforcement facilities). In FY 2019, IHSC provided direct patient care to approximately 16,500 ICE detainees at 23 detention facilities (DHS, 2019). IHSC manages health care services at these 23 facilities via an electronic health records system (IHSC, 2019). The contracted detention vendor typically handles health care at the remaining ICE detention facilities either on-site, where costs are included in the detention contract, or offsite, where costs are processed by the VA Finance Services Center, approved by IHSC, and paid for by ICE (DHS, 2019). IHSC provides health oversight for detainees housed at these facilities.

ICE detention standards govern the conditions of confinement, program operations, and management expectations within the immigrant detention system (ICE, 2000, 2011, 2019). The detention standards include medical care requirements for aliens detained for more than 72 hours. The most recent standards covering the medical care requirements are as follows: 1) the 2011 Performance-Based National Detention Standards (PBNDS), which applies to facilities within the ICE detention system (used only for immigrant detention) and 2) the 2019 National Detention Standards (NDS), which update the 2000 National Detention Standards that are applied to all facilities not used solely for immigrant detention such as state and county jails. IHSC follows the 2011 PBNDS at all facilities other than family residential centers where, instead, Family Residential Standards apply. See Table 2 for the medical care requirements in the 2011 PBNDS and the 2019 NDS.

Table 2. Current U.S. Immigration and Customs Enforcement Detention Standards Covering the Medical Care Requirements for Aliens Detained for More than 72 Hours

Sovering the l	Applies to all "you dedicated facilities"	
	Applies to all "non-dedicated facilities" that are not solely used for immigration detention	Applies to facilities within the ICE detention system (only used for immigrant detention)
	ICE's National Detention Standards*** (2019)	ICE's Performance-Based National Detention Standards** (2011)
Health intake	Detainees should receive a medical screening	Detainees should receive a medical
screening	(no later than 12 hours after arrival).	screening (no later than 12 hours after arrival).
Comprehensive	Comprehensive health assessment done	Comprehensive health assessment done
health	within 14 days of arrival at facility.	within 14 days of arrival at facility.
assessment		
HIV/AIDS	Bloodborne Pathogens (Section N), HIV	Bloodborne Pathogens (Section 4):
diagnosis and	(part 2, 3):	A detainee may request HIV testing at
management	A detainee may request HIV testing at any	any time.
	time.	• All detainees with HIV shall be
	All detainees with HIV shall be evaluated for TB disease.	evaluated for TB disease.
Tuberculosis	Upon arrival, detainees will receive TB	Upon arrival, detainees will receive TB
(TB) screening	screening.	screening.
and treatment	All detainees with suspected or confirmed	All detainees with suspected or
	TB disease shall be evaluated for HIV.	confirmed TB disease shall be evaluated for HIV.
State and federal	New HIV-positive diagnoses must be	Each facility shall establish a written
reporting of	reported to U.S. government bodies	plan for the management of HIV
HIV, AIDS, TB	according to state and local laws and	infection, including reporting to state
diagnoses	requirements.	and local health departments.
	• The facility must have written plan(s) that	• The detention facility must report all TB
	address the reporting and collaboration	cases to state or local health
Release of	with local or state health departments.	departments.
medical records	Pursuant to facility policy, copies of medical records may be released by the	• Copies of health records shall be released directly to a detainee or their
incurcar records	facility health care provider directly to a	designee, at no cost to the detainee,
	detainee, or a person designated by the	within a reasonable timeframe after
	detainee, upon written authorization from	receipt of a written request from the
	the detainee (no specific form).	detainee.
	After release from ICE detention, a	After release from ICE detention, a
	detainee may submit an FOIA request for	detainee may submit an FOIA request
	copies of medical records.	for copies of medical records.
Medical	Detainee will be provided medication (15-	The detainee will be provided medication
information	day supply for TB, up to a 30-day supply for	(at least a 15-day supply for TB, at least a
upon transfer,	HIV/AIDS), referrals to community-based	30-day supply for HIV/AIDS), referrals to
removal, or	providers, and a medical care summary.	community-based providers, medical care
release		summary.

<sup>\*</sup>Original NDS issued by the Department of Justice's Immigration and Naturalization Service, ICE's predecessor.

\*\* ICE revised the 2011 PBNDS in 2013 and 2016; this table reflects the 2016 updated version.

<sup>\*\*\*</sup>This 2019 version of the 2000 NDS applies to the ICE Intergovernmental Service Agreement facilities, U.S. Marshals Service facilities used by ICE, and facilities where state and local law enforcement partners assist ICE.

Once ICE takes custody of an alien, policy requires that person be given a risk classification assessment (RCA) as early in the process as possible unless the alien is subject to mandatory detention or will be removed within five days (ICE, 2011). The RCA was developed to assist with creating uniformity in custody and release decisions.

The RCA contains questions on personal details, encounter details, supporting information, the risk to public safety, special vulnerabilities, and the risk of flight (ICE, 2011). The RCA places serious illnesses under the "special vulnerabilities" category. The instructions for the RCA under "Serious Physical Illness" state, "Assess whether the individual has been diagnosed or claims to have a serious physical illness such as diabetes, seizures, HIV, AIDS, heart problems, cancer, epilepsy, tuberculosis, or other serious illness." If the RCA recommends detention but the alien has a serious medical condition, then they are referred to a supervisor for a decision on whether to detain or release that person.

Upon release or removal from ICE custody, the 2011 PBNDS and the 2019 NDS require that the detainee be provided medication, referrals to community-based providers as medically appropriate (the guidelines do not clarify if the providers are in the place of arrival of the alien being repatriated or in the home geographical area of the repatriated alien), and a detailed medical care summary. This summary should include instructions that the detainee can understand and health history that would be meaningful to future medical providers (ICE, 2011, 2019).

#### ICE Health Care: Tuberculosis

The primary way that ICE identifies the presence of tuberculosis (TB) is through the health screening performed when an alien is placed in detention for more than 72 hours (ICE, 2011, 2019). The 2011 PBNDS and the 2019 NDS require that all aliens receive a TB screening

following CDC guidelines within 12 hours of arriving at the detention facilities. A medical professional or a specially-trained detention officer may administer the screening. Detainees with possible TB symptoms are placed in a functional airborne infection isolation room with negative pressure ventilation and are evaluated for TB disease. If the TB screening is negative and the detainee is asymptomatic, the detainee can join the general population of detainees. Detention facilities are not required to screen detainees in the continuous custody of a law enforcement agency and who have a documented TB screening within the past six months. Annual TB tests are required for any alien in detention for more than one year.

For TB, the 2011 PBNDS require the following:

Detainees with symptoms suggestive of TB, or with suspected or confirmed active TB disease based on clinical and/or laboratory findings, shall be placed in a functional airborne infection isolation room with negative pressure ventilation and be promptly evaluated for TB disease. Patients with suspected active TB shall remain in airborne infection isolation until determined by a qualified provider to be noncontagious in accordance with CDC guidelines. (ICE, 2011)

The 2011 PBDNS and the 2019 NDS include numerous procedural safeguards for managing confirmed and suspected cases of active TB (ICE, 2011). For instance, the detention facility must report all TB cases to state or local health departments. The facility must also notify the IHSC Public Health, Safety, and Preparedness Unit (PHSP) and provide biographical information, a case summary report, and a treatment status and start date. The detention facility must notify the IHSC PHSP of any hospitalizations, facility transfers, releases, or removals of the person with TB. ICE typically does not treat detainees for latent TB infection unless they have a complicated condition, such as HIV.

When ICE removes a detained alien who has TB from the United States, the detention facility is required to coordinate with the IHSC PHSP to help ensure continuity of care (ICE, 2011). This typically occurs through a referral to the health department in the receiving country.

ICE has no authority to enforce this referral, either on the part of the alien or the part of the foreign government or health department.

According to the 2011 PBDNS and the 2019 NDS, detainees must be educated about their TB treatment and provided with a 15-day supply of medications when transferred, released, or removed (ICE, 2011, 2019). Once in their country of origin, aliens may travel to, or reside in, a location where they have limited access to health care, have limited funding to buy medication and pay for treatment or cease treatment if they do not feel sick. Providing a 15-day supply of TB medications is an effort to address concerns about incomplete TB disease treatment after removal. Interrupted TB treatment can result in a return to a contagious state, acquired drug resistance, transmission of the disease, and poor outcomes, including death (CDC, 2019).

In November 2002, the Advisory Committee for the Elimination of Tuberculosis (ACET) recommended that a working group be formed to review problems with post-detention TB treatment of aliens. ACET recommended that removal should only occur after verifying that necessary treatment is available at the destination (Nolan et al., 2003). In 2004, ICE implemented a policy allowing for a temporary "medical hold" so that the IHSC could arrange for continuity of care before removal (Fenton & Castro, 2006). In 2005, ICE formalized policies for referring medical cases to two organizations: CureTB (San Diego County Health Department, San Diego, CA) or TB Net (Migrant Clinicians Network, Austin, TX) (Schneider & Lobato, 2007).

TB Net, created by the Migrant Clinicians Network in 1996, provides continuity of care through case management of highly mobile TB patients, such as repatriated aliens (Combellick et al., 2011). According to TB Net, aliens make at least two major moves: from the detention center to their country of origin and/or from their place of arrival to their home in their country of origin. TB Net uses a caseworker to keep in telephone contact with the repatriated patients and

with their health care provider (located at their place of final destination after repatriation) to ensure that the patient is continuing treatment.

CureTB is "a referral and continuity of care program for tuberculosis patients and their contacts who travel between the United States, Mexico, and Central America" (San Diego County Health and Human Services Agency, 2019). CureTB functions as an information exchange and facilitation service. It educates aliens and connects them with TB clinics in their destination country and provides clinical information to the receiving clinics. CureTB also provides follow-up case information to the referring entity every two months and a final report after 12 months.

Notable differences exist between TB Net and CureTB. TB Net requires patient consent as a prerequisite for enrollment in the program. No written patient consent is required for enrollment in CureTB, just a provider referral. TB Net has more contact with deported TB patients, while CureTB is more involved in active case management, such as reviewing treatment plans and records.

Removal from the United States presents many challenges to TB treatment. In 2001, CDC noted, "One of the most challenging tasks in managing TB among detainees is the coordination of care during the post-detention period in the United States or in the patients' countries of origin" (Saunders et al., 2001). The fact that different countries use different definitions for active TB complicates the international referral process. The situation could result in repatriated aliens with TB no longer receiving treatment once they arrive in their country of citizenship. For example, a case diagnosed as active TB in the United States might not be active TB in Mexico. To help address this, CDC worked with its Mexican counterparts to create a binational case definition that was finalized in 2018 (Woodruff et al., 2018).

# ICE Health Care: HIV/AIDS

The two broad categories of HIV-related activities within the ICE health care system are screening for HIV and care for detainees living with HIV/AIDS. For HIV/AIDS, the 2011 PBNDS and the 2019 NDS require opt-in HIV screening (i.e., requested by the detainee) or relies on the detainee to share information on HIV/AIDS-infection upon arrival to detention (ICE, 2011, 2019). The exception is for cases where a detainee has active TB. In the latter case, the detainee must be evaluated for possible HIV infection.

According to the 2011 PBNDS, the following must occur:

A detainee may request HIV testing at any time during detention. Facilities shall develop a written plan to ensure the highest degree of confidentiality regarding HIV status and medical condition. Staff training must emphasize the need for confidentiality, and procedures must be in place to limit access to health records to only authorized individuals and only when necessary. The accurate diagnosis and medical management of HIV infection among detainees shall be promoted. An HIV diagnosis may be made only by a licensed health care provider, based on a medical history, current clinical evaluation of signs and symptoms, and laboratory studies. Clinical Evaluation and Management Personnel shall provide all detainees diagnosed with HIV/AIDS medical care consistent with national recommendations and guidelines. Medical and pharmacy personnel shall ensure the facility maintains access to adequate supplies of FDA-approved medications for the treatment of HIV/AIDS to ensure newly admitted detainees shall be able to continue with their treatments without interruption. (ICE, 2011)

Since 1987, CDC has regularly reported in the literature on HIV concerns in prisons (Westergaard et al., 2013). In contrast, relatively little research has examined HIV in U.S. immigration detention centers. According to Venters et al. (2009), ICE does not record, monitor, nor report information about HIV tests nor statistics concerning the percentage of positive tests, the stage of HIV at diagnosis, treatment initiation, and follow-up. Because ICE does not have a mandate to provide statistics on HIV, limited data are available on HIV testing and medical care for detainees. In other words, while ICE has an ongoing active TB surveillance program, it does not have one for HIV. One reason for this difference could be that ICE personnel are at-risk for

TB infection, whereas ICE personnel who feed, escort, directly supervise, or conduct routine office work with HIV patients are not considered at risk for HIV infection from a detainee. Maintaining uninterrupted HIV continuity of care among aliens removed from the United States is challenging. While ICE policy requires that repatriated aliens be given up to a 30-day supply of HIV/AIDS medication and be provided with a medical care summary, ICE referrals do not routinely happen for HIV.

# Why Compare Active TB and HIV/AIDS?

Several similarities exist between how HIV/AIDS and active TB are handled within ICE detention that have led this investigator to learn from the TB care transition model informing the HIV care transition model as follows:

- ICE requires HIV screening for all cases where a detainee has active TB. Given that ICE only provides detainee-requested HIV screening, the requirement for HIV screening for detainees with active TB could mean (in the absence of available data) that many of the HIV cases detected in ICE custody are among those with active TB. This has implications if comparing the care transition plans put in place for active TB and HIV/AIDS, potentially for the same detainee.
- The 2011 PBNDS places both active TB and HIV/AIDS in the same category—defining them as "medical conditions requiring ongoing therapy."
- The 2011 PBNDS classifies HIV, AIDS, Multi-drug resistant (MDR)-TB, and extensively-drug resistant (XDR)-TB disease in the same way—as "medical conditions that may be considered to constitute serious physical illness."

• Fourth, both active TB screening and HIV/AIDS screening are afforded considerable discussion in the 2011 PBNDS and the 2019 NDS. Although they have different protocols in place, both are complicated to treat and require special attention from IHSC. Also, ample differences exist between the two diseases that led this investigator to explore in the discussion section of this dissertation regarding other models for care transition that might better inform HIV care transition for returned aliens. For example, TB is time-limited (if treated properly), whereas HIV is a chronic condition that requires a lifetime of treatment.

# Significance

While the political debate about immigration is in the spotlight, the effect of alien removals on public health and, in particular, binational continuity of HIV care has received little attention. While ICE provides opt-in HIV screening (requested by the detainee) and treatment while in ICE custody, a major gap exists in care transition for HIV-infected detainees once removed from the United States. Currently, a process does not exist for linking HIV-infected ICE detainees with continued HIV care and treatment upon removal from the United States. Protecting the health of detained aliens removed to Mexico by ICE can offer positive health benefits for both countries, particularly by mitigating the spread of HIV in the aliens' place of arrival, their home in Mexico, and in U.S. communities. However, removal from the United States does not mean the alien will never again be a member of a U.S. community. In FY 2018, CBP reported that Border Patrol caught 11% of aliens apprehended more than one time within the same FY (U.S. CBP, 2019). Given the size, mobility, and binational nature of the deported alien population in Mexico, ensuring HIV care transition can not only protect the aliens' health by maintaining viral suppression but lower the risk of transmitting the disease to others as people who are virally suppressed have effectively no risk of transmitting HIV.

# **Conceptual Model**

This exploratory research study focused on continuity of care for detained HIV-infected aliens removed to Mexico by ICE. The major outcome of the research was to identify feasible policy proposal(s) to present to key decision-makers who can address the issue. Many policymaking frameworks are available that attempt to explain why and how specific policies get adopted. The investigator reviewed six frameworks to winnow it down to three potential frameworks—and ultimately one—that informed this research. The three conceptual frameworks considered for this study were: 1) Rogers' diffusion of innovation (DOI) (1962, 2003); 2)
Ostrom's institutional analysis and development (IAD) (1990); and 3) Kingdon's multiple streams framework (MSF) (1984, 1995). Table 3 provides comparative information for each.

**Table 3. Comparison of Three Policy Process Conceptual Models** 

Concept Model		Kingdon's Multiple Streams Framework (1984, 1995)	Ostrom's Institutional Analysis and Development (1990)	Rogers's Diffusion of Innovation (1962, 2003)
Scope Policy Development and Choice			Institutional Policies and their Outcomes	Policy Diffusion
Focus	Focus  Three "streams" (problems, policy, politics) that come together during "windows of opportunity" to cause major policy change		Conditions that lead to collective action and principles of governance	Determinants of policy diffusion and adoption
Level o analysi		System	Collective action venue (e.g., coalition, network)	Policymaking venues (e.g., legislature)
		Policymakers	Primarily individuals	Policymakers; officials; interest groups
Ideas	Ideas  Policy solutions proposed and amended over time to become acceptable to a policy community	Shared norms of actors	The norms of policy adoption that influence policy borrowers	
National mood conditions, pre	National mood, policy conditions, pressure groups, administrative turnover	Community characteristics, material conditions	Conditions (e.g., socioeconomic, ideology, religious) that affect how people can act and which rules can be set	
Relationsl among k variable	key	The interaction between two kinds of ideas: the type of policy solution that could draw attention and quickly catch on, and the established set of	Considers questions related to how rules are crafted and how they affect human behavior. Issues of policy formulation arise under this framework as do questions	Emphasizes the stages of the policy process.

DOI focuses on the norms of policy adoption and its diffusion (e.g., from one state to another). It explores the conditions, such as socioeconomic or ideological, that affect which policies get used and adopted by others. IAD focuses on "collective action" problems, such as the provision of health care or the challenges associated with coming to an agreement around a set of rules that could benefit a group. IAD offers a roadmap to analyze how institutional choices are implemented, but it does not offer a roadmap to design a policy that addresses the collective action problem. MSF is a tool for understanding how agenda-setting happens (i.e., how issues become prominent on policy agendas). It does not focus on the later stages of the policy process. In the framework, three separate streams (problems, policies, and politics) come together during a "window of opportunity" to result in public policy. The MSF enables a study of policy generation. It also helps to explain why some political issues receive attention while others do not.

To help guide this work, the investigator used Kingdon's (1984, 1995) MSF as the theoretical reference point because the research focused on developing policy recommendations to address the research question, presented in Figure 1. Because the IAD framework is most helpful to explore institutional policies, it was not a clear match for this exploratory research focused on developing policy recommendation(s). Similarly, DOI's emphasis on policy diffusion would be more helpful as a framework once policy is implemented, which was downstream from the goal of this research. In MSF, the role of problem definition is important—"how does a given condition get defined as a problem for which government action is an appropriate remedy?" (Kingdon, 1995). This perspective was congruent with the intended focus explored in this

dissertation, later addressed in Chapter 6 (Plan for Change). This is why the investigator selected MSF.

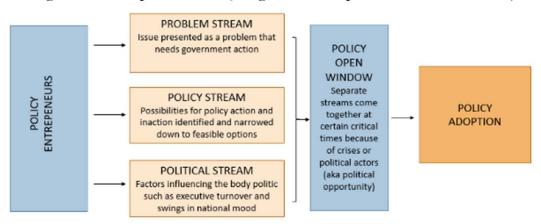


Figure 1. Conceptual Model (Kingdon's Multiple Streams Framework)

According to Kingdon (1984, 1995), the development of public policy consists of a series of processes including at least (a) setting the agenda; (b) specifying policy alternatives from which to choose; (c) making an "authoritative choice" (1995, p. 3) among alternatives by, for example, a legislative vote or presidential decision; and (d) implementing the decision. To understand these processes of policy formation, Kingdon described three normally separate independent streams that are encouraged by individuals, political action committees, and/or other organizations and stakeholders (aka policy entrepreneurs) who take advantage of opportunities to influence policy outcomes as follows:

• The **problem stream** (in which various issues compete for attention and priority on policymakers' agendas). Problems are policy issues, which are deemed to require attention. Problems get attention based on how they are framed. In some cases, issues receive attention because of a crisis or a change in the scale of the problem. Only a tiny fraction of problems receive policymaker attention. Getting attention is a major achievement that must be acted upon quickly before attention shifts elsewhere. One

- action could be to demonstrate that a cheaper, easier, more feasible, and/or politically palatable solution already exists.
- The **policy "solution" stream** (in which various policy ideas for addressing particular problems are floated, tested, discussed, revised, and packaged). Kingdon described ideas in a "policy primeval soup," evolving as they are proposed by one actor then reconsidered and modified by a large number of participants. Widely-accepted solutions in anticipating future problems are the norm until there is a good time to exploit or encourage particular attention to a relevant problem.
- The **political stream** (in which key decision-makers in the legislative or executive branch propose, debate, enact, or resist specific policy initiatives). In this stream, policymakers have to pay attention to the problem and be receptive to the proposed solution. They may supplement their own beliefs with their perception of the "national mood" and the feedback they receive from interest groups and political parties. In some cases, only a change of government may be enough to provide a motive for policymakers to take up a proposed policy solution.

The MSF does not see policymaking as linear; instead, each of the streams exists continuously and independently and may become coupled only when a "window of opportunity" opens. Because of this, feasible policy solutions can be developed before a problem is highlighted, problems are often defined and redefined, and politicians may champion a cause before its time has come. The process, at times, appears random, but Kingdon argued that there are conditions that structure and constrain it. For example, not all problems have an equal chance of getting on the agenda; rather, focusing events propel some forward while others are ignored. Additionally, not all policy proposals surface. In the political stream, some groups have more

visibility, some policymakers more power. Other constraints include the scarcity of "open windows" and the receptivity of the national mood.

Kingdon's (1984, 1995) MSF was well suited for this study because the focus of this exploratory research was to identify at least one viable policy solution that will be ready for action when a "window of opportunity" presents itself. Given the amount of recent news coverage about alien movement to and from the United States, it seems probable that the "political stream" and "problem stream" will continue to churn while the "policy stream" is finalized. It could be that "windows of opportunity" will open over the next few years that will afford the possibility for policy adoption to address HIV care transition for aliens removed by ICE to Mexico.

Because the MSF model does not address how the three streams (problems, policy, politics) intersect and interact, the discussion section of the dissertation explores the ultimate applicability of this chosen framework along with limitations.

#### **Definitions**

The alien population that this research focuses on are those aliens detained in the interior of the United States by ICE. While there are asylum seekers in ICE detention, CBP handles the majority of aliens seeking asylum at U.S. ports-of-entry and so are managed in ways external to ICE detention. Therefore, this research did not focus on them. The terminology used in this research was consistent with that of the U.S. federal government. All terms below came from the glossary of U.S. Citizenship and Immigration Services (U.S. USCIS, 2019) unless otherwise noted.

• *Alien* refers to any person who is not a citizen or national of the United States.

- *HIV and tuberculosis care transition*, for this specific research project, refers to the coordination and continuity of health care for HIV—and/or active TB-infected aliens removed from immigration detention in the United States to Mexico.
- *Immigration detention* is the policy of holding aliens awaiting judicial or legal proceedings or repatriate them to their country of departure.
- *Removal* occurs when the federal government orders that an alien be expulsed from the United States. This expulsion may be based on the grounds of inadmissibility to the United States or deportability for a violation of immigration law. ICE removals include both aliens arrested by ICE and aliens who were apprehended by CBP and turned over to ICE for repatriation efforts.
- *MDR-TB*, or *multi-drug resistant TB*, is a type of TB caused by mycobacterial strains showing *in vitro* resistance to at least isoniazid and rifampicin, the two most potent first-line drugs for TB treatment (World Health Organization, 2011).
- *XDR-TB*, or *extensively drug-resistant TB*, is caused by mycobacterial strains showing *in vitro* resistance to isoniazid and rifampicin plus any fluoroquinolone and at least one of the injectable second-line drugs: amikacin, capreomycin, or kanamycin (World Health Organization, 2011).

# **Research Question**

The primary research question was as follows: How can HIV care transition be improved when U.S. Immigration and Customs Enforcement repatriates detained aliens to Mexico? The research in this dissertation was exploratory, and the goal was to understand how HIV care transition can be improved for detained aliens removed by ICE to Mexico. This exploratory research addressed three aims: 1) explore the current quality of HIV care transition for detained

HIV-infected aliens removed to Mexico by ICE; 2) identify challenges impacting the HIV care transition for this population; and 3) explore lessons from tuberculosis care transition that can be applied to HIV.

## **Research Interests**

The investigator possesses extensive experience and a strong interest in health concerns in the U.S.-Mexico Border region. As a former project officer for the U.S.-México Border Health Commission (USMBHC), a binational Presidential commission co-chaired by the Secretaries of Health of both the United States and Mexico, the investigator gained an appreciation for the opportunities and challenges associated with working bi-nationally on infectious disease information sharing. The specific question for this dissertation—how to improve HIV care transition for HIV-infected aliens removed from the United States to Mexico—was conceived in 2013 as a result of work conducted during her tenure at the U.S. Department of Health and Human Services (HHS) Office of the Secretary. Unfortunately, the investigator was unable to fully address this question at the time and, as a result, this question is being addressed now.

## **CHAPTER 2: LITERATURE REVIEW**

## Methods

# Information Sources

The investigator conducted this research to understand the current quality of HIV care transition for HIV-infected aliens removed to Mexico from the United States, challenges impacting HIV care transition for this population, and whether lessons exist from TB care transition that can be applied to HIV. A systematic search was conducted using the following databases: (1) Medline, (2) Embase, (3) PsycInfo, (4) CINAHL, (5) Scopus, and (6) ProQuest Central. Medline, Embase, and PsycInfo databases were accessed via Ovid. CINAHL was accessed via EBSCO Information Services. The search was restricted to publications in English. In addition, bibliographies of retrieved articles were hand-searched. The search terms used are described below in Table 4.

**Table 4. Search Terms for Literature Review** 

Date Limitations: 1996 to the Present		
Concept Key words, search terms		
Detained immigrant Undocumented immigrants/AND (detained OR detention).ti,ab.) OR		
(detain*adj5 (migrant* or immigrant* or refugee* or alien)).ti,ab.OR		
(detention*adj5(migrant* or immigrant* or refugee* or alien)).ti,ab.		
AND		
Health while detained, specifically	Health* OR medical OR HIV OR TB OR tuberculosis	
HIV and TB		
AND		
Location	United States, Mexico	

<sup>\*</sup>Presented for Ovid search, slightly modified for EBSCO Information Services, Scopus, and ProQuest Central

#### Inclusion and Exclusion Criteria

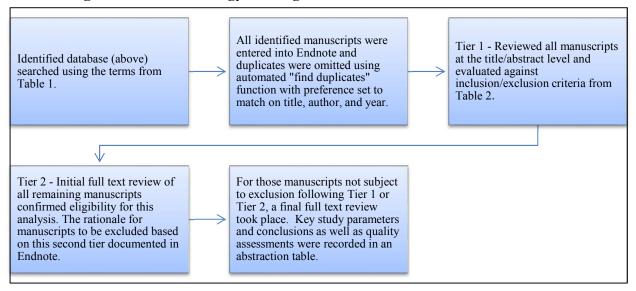
Only those studies published since the September 1996 enactment of IIRIRA were reviewed. Table 5 details inclusion and exclusion criteria used.

Table 5. Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Be written in English	Not written in English
Be a full-text article	Not full-text
Peer-reviewed publications or high-quality grey literature	Low-quality grey literature
(i.e., includes methods)	
Source is original, empirical study designed to measure	Source is not original, empirical work (i.e.,
the effect of a policy, practice, or intervention	conference proceedings, abstracts, systematic
	reviews, meta-analyses)
Published between September 1, 1996 and October 15,	Published before September 1, 1996
2018	
Study examines the HIV and/or TB care continuum	Study does not examine the HIV and/or TB care
within the immigration detention system in the United	continuum within the immigration detention system
States and/or upon repatriation to an alien's home	in the United States and/or upon repatriation to an
country	alien's home country

The search strategy to integrate these criteria is described below in Figure 2.

Figure 2. Search Strategy to Integrate Inclusion and Exclusion Criteria



# Study Selection

The eligibility assessment of articles was performed independently in a standardized manner by one reviewer. The absence of multiple reviewers was a limitation and area of potential bias for this review. All articles identified through the information sources collection process were imported into Endnote, a reference manager software, for screening by the reviewer based on titles and abstracts. Full-text articles were reviewed and designated whether they met

the inclusion criteria or not. Duplicates were removed automatically from Endnote, but the reviewer also looked for duplicates during the review process as well. The articles remaining after all exclusion criteria were applied and reviewed in full of key information.

#### Results

The primary search strategy yielded 236 articles from search engines. Articles were entered into Endnote and then Covidence for de-duplication. This led to a total of 162 articles. The initial title and abstract review excluded 150 articles, leaving 12 eligible for full-text review. An additional two articles were identified through bibliographic references. In the full-text review, three articles were excluded for the following reason: the study did not examine the HIV and/or TB care transition within the immigration detention system in the United States and/or upon repatriation to an alien's home country (n=3). Eleven articles were included in this review, as presented in Figure 3.

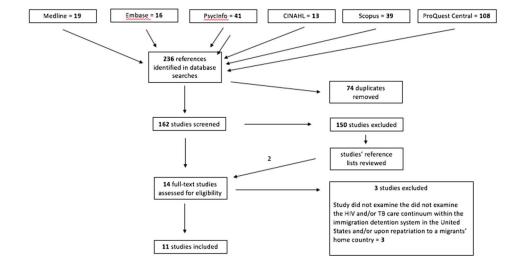


Figure 3. PRISMA Diagram

## Rates of HIV Infection among Aliens Detained by ICE and Removed to Mexico

The effect of removals on public health and the binational care transition has received little attention. One reason is the lack of data to assess the extent of the problem (Page et al.,

2018). Little is known about the prevalence of HIV infection and risk factors among aliens removed by ICE to Mexico. Information on immigration status is often unavailable in HIV epidemiological studies on Mexican migrants in the United States. Estimates of HIV infection and related risk factors among deported Mexican migrants are challenged by methodological difficulties to reach representative samples of this highly mobile population in Mexico (Page et al., 2018).

Researchers and practitioners have to use other methodologies to calculate the prevalence of HIV in those persons ICE repatriated to Mexico. Rangel et al. (2012) conducted a cross-sectional survey with deported Mexican migrants in Tijuana, Mexico (N=693) and estimated levels of HIV infection in this population. Results indicated a 0.8% prevalence of HIV infection among deported males, more than twice that estimated for the adult population in Mexico (0.3%) (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2017).

# Barriers for HIV Care Transition for HIV-Infected Aliens Removed to Mexico

According to Page et al. (2018), maintaining uninterrupted continuity of care among aliens held in U.S. detention or removed to their home countries is challenging. Maintaining HIV suppression requires intensive case management, access to treatment of mental health and substance use disorders, adherence support interventions, and coordination of medical care. None of these resources are routinely available to HIV-infected aliens deported from the United States (other than a 30-day supply of antiretroviral (ART) if they were receiving therapy while detained) (Page et al., 2018). The literature search identified three main barriers for HIV care transition: 1) location of repatriation, 2) lack of medical records, and 3) lack of health insurance and access to health care among Mexican deportees.

Barrier #1: Location of Repatriation. Immigrants are typically released at the border between Mexico and the United States without identification, money, food, and shelter, and with few personal belongings (Rangel et al., 2012; Truby, 2014). Most find themselves in unfamiliar territory, far from their home communities, and for many, their immediate priority is how to reenter the United States. Clinics capable of caring for HIV-infected individuals might not be easily accessible to those immigrants interested in seeking HIV care because of distance or lack of health coverage (Page et al., 2018).

Barrier #2: Lack of Medical Records. Currently, HIV-infected detained aliens are not repatriated with the appropriate documentation to seek treatment in Mexico, such as medical records (Truby, 2014). The full list of required documents is presented herein. Mexican providers are often uncomfortable prescribing HIV treatment without previous medical records (Aids Education and Training Center [AETC], 2018). Nearly all HIV medications available in the United States are now available in Mexico (AETC, 2018). With that said, patterns of drug resistance circulated in the United States might also differ, and the first-line regimen in Mexico might be inadequate for patients with pre-existing resistance mutations (Page et al., 2018). Without access to previous medical records (including drug resistance profiles), health care providers in the receiving country might have insufficient medical history information on patients to make appropriate treatment decisions about removed aliens with drug-resistant HIV (AETC, 2018).

The United States-Mexico Border AETC Steering Team (UMBAST) is sponsored by the Health Resources and Services Administration (HRSA) Ryan White HIV/AIDS Program and is a collaboration of AETC and the U.S.-Mexico Border States: Arizona, California, New Mexico, and Texas. UMBAST has developed fact sheets to assist U.S. providers who have patients

leaving the United States for Mexico and Central American countries. The goal of the information is to improve continuity of care for migrant patients, including deportees, with HIV. According to AETC (2018), Mexican citizens must provide certain documents to be able to receive HIV medications in Mexico. The two necessary pieces of documentation are 1) a positive HIV antibody test result and 2) a patient CURP number (Mexican federal ID # or the "Clave Unica de Registro de Población"). The recommended pieces of documentation are as follows:

- A recent CD4 + T-cell count.
- A recent viral load test result.
- Medical chart copy including complete antiretroviral treatment history.

**Deportees.** Despite the growing evidence of the health challenges that confront Mexican deportees, very little is known about their access to health care upon return (Wassink, 2018). Scholars have begun highlighting especially low access to health care among recently returned migrants (Martinez-Donate et al., 2017; Wassink, 2018). However, no nationally representative

studies have investigated access to a regular source of care among Mexican deportees.

Barrier #3: Lack of Health Insurance and Access to Health Care among Mexican

Using data from a recent survey conducted in Tijuana, Mexico, Martinez-Donate et al. (2017) found that Mexican migrants (referring to both voluntary and involuntary migrants) have significantly lower health coverage and access to care upon return relative to their pre-migration levels, indicating that migration may be associated with a lapse in coverage. Wassink (2018) investigated return migrants' health insurance coverage and access to medical care using data from the 2009 and 2014 rounds of Mexico's National Survey of Demographic Dynamics (ENADID, combined n=632,678). Results suggest that health insurance coverage is especially low among those who returned within the past year, a gap that largely results from lower

employment-based coverage among return migrants, who tend to work in the informal sector of the economy. For most returned migrants, securing employment represents an immediate and pressing concern (Wassink, 2018). Relative to non-migrants, recently returned migrants rely disproportionately on private clinics, pharmacies, and self-medication. Moreover, reliance on private clinics and pharmacies places return migrants at increased risk of incurring catastrophic medical expenses and going without medical care, especially preventive treatment (Wassink, 2018).

These findings highlight the need for targeted policies aimed at 1) re-integrating Mexican deportees into the labor market, which may have broader benefits for their reintegration into important services, such as health care, and 2) ensuring all removed aliens have access to their Mexican federal ID number, known as the CURP (Clave Única de Registro de Población). The CURP is needed to receive health care under Mexico's el Instituto Nacional de Salud para el Bienestar or the Health Institute for Wellbeing in English, commonly referred to as INSABI. This new program, INSABI, replaced Seguro Popular (the People's Insurance) on January 1, 2020. Seguro Popular was a universal health insurance program designed to complement Mexico's employment-based social security program. INSABI is designed to provide comprehensive coverage for everyone, at any hospital or clinic belonging to Mexico's public health system at no cost to the patient. All medications are covered, including HIV/AIDS treatment. Under INSABI, there is no enrollment needed. To access Mexico's public health system, the patient must present their CURP or birth certificate at the health care facility.

# Key Components of Binational HIV Care Transition

The literature on disease and borders nearly unanimously promotes binational collaboration as a policy objective, focusing on information sharing and disease monitoring (Truby, 2014). The literature search identified two main components for successful HIV care transition: data-sharing policies and engagement with civil society.

Component #1: Data-Sharing Policies. Developing legally and ethically sound data-sharing policies to strengthen the coordination of care transition between the United States and Mexico is crucial to ensure binational HIV care transition. These policies are not straightforward to implement but models are available that can be instructive, including TB models. Currently, ICE does not have an HIV surveillance system (Venters et al., 2009). Methods of data collection and identification of detained aliens infected with HIV removed to Mexico (compliant with patient autonomy and protection of confidentiality) should be improved (Page et al., 2018).

Component #2: Engagement with Civil Society. Truby (2014) examined how HIV-focused civil society organizations operate at Mexico's northern border. The nature of ICE repatriation and of temporary, mobile populations create challenges for addressing HIV/AIDS. Many HIV-infected deportees avoid government institutions, making them more likely to avoid state assistance, and experience a temporary, unsettled life at the border (Truby, 2014). Hostility in the Mexican state and local debates (regarding immigrant access to services) has fueled a climate that deters lawfully present immigrants from securing health services (Truby, 2014). It is for these reasons that civil society organizations might be better equipped to serve as first-line defenses in the fight against HIV/AIDS at the border. However, without sufficient CAPASITy and resources, civil society organizations cannot control the epidemic unilaterally.

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According to Truby (2014), the receiving country should establish initiatives to facilitate the reintegration of patients into their health care system, including confidential assistance for all HIV-infected aliens removed to Mexico by ICE should be provided immediately upon their return. According to Page et al. (2018), the establishment of these focused initiatives is essential for linking deportees to health and social programs in Mexico to which they might be entitled.

Local collaborative partnerships between the Mexican government, community-based organizations, public health departments, and investigators on both sides of the border have been developed to provide access to basic medical services and HIV prevention resources to deportees. Rangel et al. (2012) identified that what these programs do not include are initiatives to increase the availability of financial, social, and emotional support for recent deportees as they are released in the U.S.-Mexico border region.

## Coordinating Care Transition for TB-Infected Aliens Removed to Mexico

TB patients crossing national borders face an array of challenges in cross-border TB control. These include limited access to early TB diagnosis, a lack of continuity of care for TB patients when they move to another country, and no or little information to the health providers in the countries of transit, destination, and return (Schneider & Lobato, 2007). Often a lack of appropriate and/or adequate information exists for patients as to their rights, availability of health services, coverage entitlements, and accessibility of services. In some countries, there is no provision for the coverage of TB diagnosis and treatment costs, which mainly rely on individual payment. These are further complicated by cultural and language barriers and stigma.

Although there are programs and pilots aimed at creating a framework for cross-border collaboration for TB care transition, academic publications on the topic are scant. Two national working groups, convened by CDC, have published reports that address the public health

importance of the continuity of TB therapy for TB-infected aliens in ICE custody (Schneider & Lobato, 2007). A governmental ad-hoc working group was established in 2002 to address concerns regarding detained TB-infected aliens who experience interruption of TB therapy when removed to Mexico by ICE (Fenton & Castro, 2006). With guidance from this working group, ICE established policies and procedures for collaborating with TB control programs, foreign national TB programs, and programs that facilitate international TB referrals, continuity of care, and treatment completion. Through these collaborations, ICE detainees with confirmed or suspected TB disease are routinely enrolled in CureTB (San Diego County Health Department, San Diego, CA), and TB Net (Migrant Clinicians Network, Austin, TX).

Dara et al. (2012) described the minimum package of cross-border TB control and care elements to address the issues identified herein. The resulting consensus document outlines four components to address the current shortcomings and enhance the coordination of transnational continuity of care for patients with TB, presented in Table 6. Consensus was reached to indicate that three working days' notice comprised the maximum time necessary to share information on the patient moving from one country to another.

Table 6. The Minimum Package for Cross-Border TB Control and Care

Element	Components	Considerations	
Governance	<ul> <li>Legal framework</li> <li>Funding</li> <li>Inter-country correspondence</li> </ul>	<ul> <li>Commitment to cross-border control and care; ensure legal basis</li> <li>Ensure funding from government resources, health insurance, and/or bilateral and multilateral funding (treatment should not be at cost to the patient)</li> <li>Create a list of live TB service providers to be maintained by a "reference center" in each country specifically identified with this task</li> </ul>	
Service delivery	<ul> <li>Prevention</li> <li>TB infection control</li> <li>Diagnosis</li> <li>Treatment</li> <li>Continuity of care</li> </ul>	<ul> <li>Diagnose and treat latent TB infection, irrespective of patients' legal status (note: ensure treatment of drugresistant TB and TB/HIV co-infection)</li> <li>Pursue early diagnosis</li> <li>Provide prompt and effective treatment</li> <li>Do not deport before the end of treatment, or at least until the end of intensive phase, and ensure continuation phase treatment will be followed</li> </ul>	
Surveillance and monitoring	<ul> <li>Individual patient data</li> <li>Program performance</li> </ul>	<ul> <li>Effectively transfer patient's medical record</li> <li>Provide sufficient TB medications to ensure treatment until the patient's care is resumed</li> <li>Provide feedback to the center sending the patients</li> <li>Collect data for indicators at the country and regional level to measure progress (example indicators include: # of TB patients diagnosed as having TB before moving to another country, # of TB patients who crossed the border and successfully completed treatment)</li> </ul>	
Supportive environment	<ul> <li>Enablers and incentives</li> <li>Advocacy communication and social mobilization</li> </ul>	<ul> <li>Provide counseling and psychosocial support to patients</li> <li>Empower communities to provide migrant-sensitive services</li> <li>Improve communication with civil society, migrant communities</li> <li>Advocate for full engagement of health authorities and stakeholders</li> <li>Ensure cross-border monitoring mechanisms are in place</li> </ul>	

Source: (Dara et al., 2012)

Schneider and Lobato (2007) reviewed TB cases reported for ICE detainees from 2004-2005. They found that during 2004 and 2005, 76 and 142 TB patients were reported, respectively. Detainees from Mexico and Central America accounted for 84.4% (184) of the cases. TB-infected detainees spent an average of 82.6 days in treatment before release or repatriation back to their home country of record. The study concluded that because detained, active TB-infected aliens are usually deported before completing TB therapy, and sometimes reenter the United States, unique collaborations are required to support completion of treatment.

Tschampl et al. (2016) estimated the proportion of removed aliens who received transnational TB care—continuity services by using case management data from the two-provider organizations. Approximately 10% of removed aliens received transnational continuity of TB care services. Thus, ~90% of TB-infected aliens departed the United States without such services, a finding that highlights a neglected public health area and the feasibility of scaling up intervention. A related and somewhat encouraging finding was that 67% (124/186) of TB-infected aliens receiving transnational services were among those detained before removal. Assuring all who are removed receive transnational services is another way to avoid treatment interruption and development of drug-resistant TB.

One Mexican Program in Place to Address Binational AIDS Care Transition

Mexico's Outpatient AIDS Clinics (CAPASITS, the Spanish acronym which stands for "Centro Ambulatorio de Prevención y Atención en SIDA e ITS"). The CAPASITS network was introduced in Mexico in 2005 and is still expanding (AETC, 2018; Truby, 2014). As of 2016, it comprised 76 centers around the country (AETC, 2018). The Mexican federal agency in charge of HIV treatment and prevention, CENSIDA, operates a national toll-free hotline for people, including deportees, to call when they are in Mexico to find the closest care provider. All HIV-positive patients can be seen at CAPASITS for three months without a Mexican federal ID number (CURP).

#### **Discussion**

Binational HIV care transition is complex. Creating a robust public health approach to facilitate HIV care transition among detained aliens removed to Mexico by ICE will require political will and financial commitment from the United States and from Mexico. The literature

results highlighted several key components of the continuity of HIV care that must be put in place.

Within ICE facilities, methods of data collection and identification of detained aliens infected with HIV (compliant with patient autonomy and protection of confidentiality) should be improved to monitor care transition for deportees. Developing legally sound data-sharing policies that strengthen the coordination of linkage to care between both countries is crucial to ensure the continuity of HIV care across the shared border. These policy changes are not straightforward to implement, but there are TB models available that can be instructive.

The consensus document (Dara et al., 2012) outlining recommendations for coordinating transnational continuity of patient care with TB highlights key elements, including political commitment (e.g., a legal framework for cross-border collaboration), adequate governance and financial mechanisms, surveillance and monitoring, and adequate health service delivery. In the United States, TB Net coordinates continuity of care for migrant populations and has facilitated care coordination for over 1,500 migrants from the United States with active TB (Page et al., 2018). The Network provides a HIPAA-compliant platform to share medical records with international providers and link patients to care through virtual case management. CDC cooperates with ICE to coordinate care for active TB cases across borders.

On the receiving end, Mexico needs to enhance initiatives to facilitate the reintegration of deportees into its health care system. The literature review revealed limited access to medical care among recently returned migrants (Martinez-Donate et al., 2017; Wassink, 2018).

Assistance for all HIV-infected deportees immediately upon their return is essential to link them to health and social programs to which they might be entitled. A need exists for targeted policies to facilitate successful reintegration and ensure access to vital resources such as health care.

Mexico's civil society organizations might be best equipped to engage with recent deportees and link them to care (Truby, 2014).

Although the literature stresses the need to increase HIV testing and treatment in border communities, the transitory existence of the deportees makes treatment and adherence difficult (Truby, 2014). Continuation of both HIV and TB care between countries should occur through a shared updated list of HIV and TB services and national focal points for effective and timely communication regarding transferred active TB cases.

The literature review presented clear challenges for HIV care transition, areas for opportunity, and examples to examine further. The adaptation of the TB framework presented in Chapter 4 (Results and Discussion) will be explored through the key informant interviews.

#### **CHAPTER 3: METHODOLOGY**

### **Study Design and Methods**

This dissertation included both a qualitative and a quantitative study to address the following research question: How can HIV care transition be improved when U.S. Immigration and Customs Enforcement repatriates detained aliens to Mexico? An exploratory convergent mixed-methods design was employed, presented in Figure 4. Mixed methods research is "an approach to inquiry involving collecting both quantitative and qualitative data, integrating the two forms of data, and using distinct designs that may involve philosophical assumptions and theoretical frameworks" (Creswell & Creswell, 2018). A convergent mixed-methods design means that data collection occurred simultaneously but separately.

**Convergent Mixed Methods Data Collection** Procedure: Collect HIV Procedure: Nine key informant QUALITATIVE QUANTITATIVE prevalence data interviews Product: Nine interview Product: Data tables transcripts **Data Analysis** Procedure: Constant comparative Procedure: Descriptive thematic analysis Product: x number of themes QUALITATIVE QUANTITATIVE Product: Frequencies, means Procedure: Compare qualitative Product: Table relating themes **Merge Results** and descriptive statistics themes with descriptive statistics Procedure: Consider how merged Product: Discussion, Interpretation results produce a clearer Recommendations, Limitations understanding

Figure 4. Convergent Mixed Methods Design Adapted from Creswell & Creswell, 2018

Described herein are the aims and corresponding associated data collection methods of this study, arrived at under close guidance of the investigator's dissertation chair as follows:

- AIM 1: Explore how various stakeholders perceive the current quality of HIV care transition for detained, HIV-infected aliens removed from the United States to Mexico
  - o Method: Literature review; key informant interviews.
- AIM 2: Identify some of the challenges affecting HIV care transition for detained, HIVinfected aliens removed from the United States to Mexico
  - Method: Literature review; secondary analysis of quantitative data; key informant interviews.
- AIM 3: Explore whether there are lessons from TB care transition (or other models) for detained, TB-infected aliens removed from the United States to Mexico that can be applied to HIV care transition.
  - Method: Literature review; secondary analysis of quantitative data; key informant interviews.
- AIM 4: Develop a plan for change (i.e., policy agenda) that will improve HIV care transition for detained, HIV-infected aliens removed from the United States to Mexico
  - o Method: Synthesize results from aims #1-3.

One aim was not pursued because data were not available to explore the impact of challenges affecting HIV care transition have on HIV treatment adherence following the ICE removal of HIV-infected aliens to Mexico.

#### **Institutional Review Board and Confidentiality**

The proposal was reviewed and approved by the University of North Carolina (UNC), Chapel Hill Institutional Review Board (IRB). The investigator began collecting data and

conducting analyses for the key informant interviews upon approval of the UNC IRB. In addition, the investigator, currently employed by the Centers for Disease Control and Prevention (CDC), collected data as a graduate student at UNC Chapel Hill and not on behalf of the federal government (data collection was not federally-sponsored). Therefore, CDC leadership stated their reliance on the UNC IRB for review and approval of this study.

#### Sources of Material

Primary data for this study was obtained through individual key informant interviews conducted between October 1, 2019, and January 15, 2020. Secondary data (de-identified) was obtained through the Texas Department of State Health Services' annual HIV Surveillance Report for 2018, the latest year data are available, which is publicly available (Texas Department of State Health Services, 2019).

## **Informed Consent**

Informed consent was obtained verbally and recorded. With each key informant interview, I shared the consent form ahead of time and received verbal approval of consent from the interviewee at the beginning of the recording. Assurances of confidentiality were maintained throughout the study. The consent form used is available in Appendix C.

### Potential Risks and Protection against Risk

The primary risk to key informant interview participants was a breach of confidentiality. To minimize this risk, interviewees were not connected to their answers in any way. Each interviewee was issued an ID number that was used for the interview, rather than their name. Their name will not be used in any study report, final report, or publications. Once the data were compiled, all identifying information associated with their answers was removed.

Audio recordings of the key informant interviews were transcribed; names and other identifiers were not included in the transcribed copies. Electronic copies of transcriptions were stored on password-protected computers on a secure server. Keys linking names and personally identifiable information with ID numbers were destroyed once the database was complete and ready for analysis. All data was on password-protected servers until the study results were completed. All field notes were kept in a locked cabinet in the principal investigator's office. Access to print and electronic files was restricted to the study investigators. When the study results were completed, the electronic and paper data were destroyed.

### **Methodology: Quantitative Study**

To identify challenges and inform recommendations to strengthen care transition for detained HIV-infected aliens removed to Mexico from the United States and explore lessons learned from TB care transition that can impact HIV care transition, current (baseline) descriptive statistics are needed, such as the prevalence of HIV in the population of detained and removed aliens to Mexico. The most straightforward method to attain these data was to use secondary data reported in the literature.

Because no available data sources exist on HIV prevalence in the population of detained and removed aliens to Mexico, the prevalence in this population was calculated using the Texas Department of State Health Services annual HIV Surveillance Report that is publicly available and includes de-identified annual data for the years 2009 to 2018 (Texas Department of State Health Services, 2019). HIV is a notifiable condition in Texas, and ICE officials are obligated to report it to the county of which the facility is located. The report does not separate case counts by gender, race, or ethnicity.

In FY18, 32% of all aliens in ICE detention (ICE, 2019) were geographically located within the state of Texas. Using the Texas data, the investigator estimated the prevalence of HIV in ICE facilities in FY 2018, the most recent year of available HIV diagnoses on record. This data were extrapolated from the entire United States.

### **Methodology: Qualitative Study**

The descriptive statistics were supplemented with primary qualitative data obtained from nine key informant interviews of identified stakeholders (see Appendix B for the key informant interview guide). These interviews helped inform policy interventions discussed in Chapter 5 (Policy Analysis) and Chapter 6 (Plan for Change). Key informant questions explored problem and policy factors, areas of opportunity, and the role(s) of key decision-makers.

The investigator started with a list of key informants. During the interview process, they were asked if others should be included. Selection of the first five interviewees was based on personal knowledge of their high level of experience with immigration detention in the United States and/or with HIV and/or TB care transition for detained aliens removed to Mexico by ICE. After these sessions, the investigator asked each of them to recommend one to two other people who may be interested in participating or have unique perspectives. Interviewees were contacted via e-mail with a standardized introduction describing the purpose of the research, expectations for the interview, and mechanisms for ensuring the confidentiality of responses. The e-mail explained that they were not obligated to participate in the interview and that declining would have no effect on professional relationships. A second e-mail followed one week after the first to those for whom no response was received. For those with no established contact, an alternate interviewee was identified through the participants' network.

Key informant interviews were conducted by telephone. Telephone interviews were preferred rather than in-person encounters with professional key informants since professionals were likely to have demanding schedules with limited flexibility. The telephone interview was recorded (after consent was provided) to allow the interviewer the ability to focus on the responses and the informant and not on note-taking. Recorded responses were subsequently transcribed for data extraction. Each key informant interview took no longer than 35 minutes to complete; however, the interviewer allotted 45 to 60 minutes per key informant to allow the informant the opportunity to elaborate when responding to questions. The interviewer opened the call by sharing the purpose of the interview and the details of the study.

Ensuring confidentiality/anonymity is very important. To maintain confidentiality, each interviewee received a random numeric identifier, so their specific comments cannot be linked to the data. The key informants were informed that their name and title would not be used in the final report or publications and that their responses would be kept confidential—results focused on the content of the discussion rather than identifying who said what. This helped encourage them to participate and make them more willing to share their opinions about the topic openly.

The information obtained from the key informant interviews was qualitative. The analysis of the interviews focused on groupings of themes, a discussion of findings, and a presentation of conclusions. The following data analysis steps were taken with the interview recordings and transcriptions to identify themes, to compare and contrast responses across interviews, and to ultimately assess the themes emerging from the key informant interviews.

#### Step 1: Close Reading of the Data

The responses were read and re-read to gain a deeper understanding of them. The first opportunity to examine the data was through transcribing the responses. Once the data were

transcribed, the responses were reviewed a second time to reveal nuances not evident from the initial transcription.

## Step 2: Identifying Initial Codes

Codes were assigned to segments of the responses related to the research question to begin understanding themes extracted from the key informant interviews. (Note: A code was tagged to a word, a phrase, a sentence, or some larger segment of text.) QSR NVivo was used for the coding analysis. The coded data was automatically tagged to the source and placed in a file.

### Step 3: Developing Themes

All the codes were reviewed to determine how different codes might combine to form an overarching theme and subthemes. After the first-round of theme development, the themes were reviewed for refinement; some themes were collapsed, and others needed to be broken into subthemes. The target was for external heterogeneity—distinct themes that represent the dataset with clear relationships among the themes and a clear connection to the research question.

### Step 4: Drawing a Thematic Map

After developing the themes, a thematic map was drawn, visually describing the patterns and the relationships among them. The research question lies at the center of the map with themes and subthemes connected to it—and showing the relationships between the themes.

#### Step 5: Writing the Analysis

The themes from the key informant interviews were coupled with the descriptive statistics from the quantitative analysis, seeing if the merged results produced a clearer understanding of the answers to the research aims and the primary research question.

#### **CHAPTER 4: RESULTS AND DISCUSSION**

This chapter begins by describing the findings from the convergent mixed methods study:

1) secondary data from the published literature on the prevalence of HIV in the population of detained and removed aliens to Mexico and 2) key informant interviews with stakeholders presented by the three research aims. This chapter continues with a discussion on how the analysis ties back to the primary research question. Table 7 describes the four research aims and associated data and methods of the study. The chapter concludes with an overview of the limitations of this exploratory study and recommendations for further research. Chapter 5 (policy analysis) and Chapter 6 (plan for change) focus on the fourth and final aim which is to use the results in this chapter and develop a plan for change (i.e., policy agenda) that will improve HIV care transition for detained HIV-infected aliens removed from the United States to Mexico.

Table 7. Description of the Study's Four Research Aims and Supporting Methodology

Primary research question: How can HIV care transition be improved when U.S. Immigration and Customs

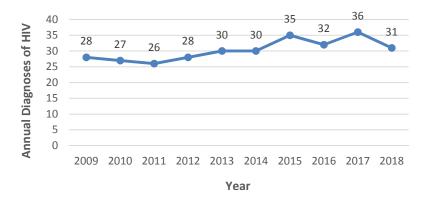
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Enforcement repatriates detained aliens to Mexico?			
Aim	Method		
AIM #1: Explore how various stakeholders perceive the current quality of HIV care transition for detained, HIV-infected aliens	-key informant interviews -literature review		
AIM #2: Identify some of the challenges affecting HIV care transition for detained, HIV-infected aliens removed from the United States to Mexico	-secondary data analysis -key informant interviews -literature review		
AIM #3: Explore whether there are lessons from tuberculosis care transition (or other models) for detained, TB-infected aliens removed from the United States to Mexico that can be applied to HIV care transition	-secondary data analysis -key informant interviews -literature review		
AIM #4: Develop a plan for change to improve HIV care transition	-synthesize results, aims #1-3		

### **Quantitative Study**

Because no available data sources exist on HIV prevalence in the population of detained and removed aliens to Mexico, the prevalence in this population was calculated using the Texas Department of State Health Services' annual HIV Surveillance Report ,which is publicly available and includes de-identified annual data for the years 2009 to 2018 (Texas Department of State Health Services, 2019). HIV is a notifiable condition in Texas, and ICE officials are obligated to report it to the county of which the facility is located. The surveillance report includes annual diagnoses of HIV (regardless of disease status, HIV-only or AIDS) in ICE facilities with data presented in Figure 5. Data presented do not separate case counts by gender, race, or ethnicity.

Figure 5. Annual Diagnoses of HIV Regardless of Disease Status (HIV-only or AIDS) in ICE Facilities in Texas Reported to the Texas Department of State Health Services, 2009-2018



According to federal government data, in FY18, Texas (15,852), California (6,527), Arizona (3,869), Georgia (3,717), and Louisiana (3,143) were the top five states with the largest number of aliens in U.S. immigration detention per day (ICE, 2019). In FY18, Texas housed 32% of all aliens in ICE detention (ICE, 2019). Texas has more detention facilities and holds more detained aliens than any other U.S. state. There are a few reasons for the high concentration of ICE aliens in Texas, including its proximity to the border (Texas shares the longest border

with Mexico of any state in the United States) and the existence of infrastructure located in jurisdictions open to contracting with ICE.

In FY 2018, ICE facilities performed 179,941 comprehensive health assessments across all of its facilities in the ICE detention system in the United States (ICE, 2019). Because cumulative figures for a total number of ICE detainees are not available by fiscal year (ICE presents data as the number of beds used each day), comprehensive health assessments are an approximate measure for the number of new detainees each fiscal year. In FY 2018, ICE facilities in Texas reported 31 diagnoses of HIV regardless of disease status (HIV-only or AIDS) (ICE, 2018). In FY 2018, ICE reported that 64.4% of detainees were Mexican aliens (ICE, 2018). Using this information, the investigator estimated the number of HIV diagnoses for all ICE detainees in the United States in FY 2018 as follows:

- (1/0.32 (percentage of ICE detainees in Texas) x 31 (HIV/AIDS diagnoses in Texas ICE facilities) = 97 detainees diagnosed with HIV in FY 2018 out of 179,941
- Given that 65.4% of ICE detainees in FY 2018 were Mexican aliens, the estimated number of Mexican detainees diagnosed with HIV in FY 2018 is 0.644\*97 = 63 (an estimated 63 HIV-infected Mexican aliens are diagnosed with HIV in ICE detention each year)

Using this estimate for the number of Mexican detainees diagnosed with HIV/AIDS in FY 2018 (63), the investigator was able to estimate the number of HIV-infected aliens repatriated to Mexico by ICE in FY 2018 as follows:

0.32 (% of detainees housed in Texas) \* 179,941 (health assessments were conducted in all facilities) = 57,581 aliens detained in Texas were tested for HIV in FY 2018

- The FY 2018 HIV prevalence among Texas detainees is 31 (detainees diagnosed with HIV in ICE facilities in Texas) / 57,581 = 0.000538 (or 5.38 x 10,000).
- Using this prevalence (0.000538) and multiplying it against the total number repatriated to Mexico in FY 2018 (141,045) = 75 detainees (an estimated 75 HIV-infected aliens repatriated by ICE to Mexico each year).

The methodology to calculate the HIV prevalence estimates for detained and repatriated Mexican aliens entailed several assumptions and limitations. The first assumption was the estimates for the total number of ICE detainees in FY 2018 diagnosed with HIV and detained Mexican aliens diagnosed with HIV were low and most likely an underestimate of the actual prevalence of HIV/ in ICE detention. This assumption was because HIV screening is at the request of the detainee (opt-in), and ICE does not screen for HIV/AIDS (unless an alien has active TB). The second assumption was that although Texas is the U.S. state with the largest ICE detainee population (32%), it is not the only state with ICE detainees, and, therefore, may not be a truly representative sample. The third assumption was that the HIV prevalence in FY 2018 could be representative of the prevalence in other fiscal years. The fourth assumption was that the rate of health assessments that involve an HIV test is the same in Texas compared with other states. The fifth assumption was that the likelihood of getting a health assessment among Texas detainees is the same for all detainees. The sixth assumption was that the prevalence of HIV among Mexican detainees in Texas is roughly the same for all Mexican detainees that may not be the case (e.g., it may be that Mexican detainees in Texas are more likely to come from a certain state in Mexico that has a higher or lower HIV prevalence than other Mexican states). Lastly, it was unclear how many of the aliens diagnosed with HIV have already been receiving HIV treatment within the Mexican health care system and, consequently, may not need HIV care

transition support to the degree that the other HIV-infected Mexican aliens repatriated to Mexico will. However, this estimate of 75 HIV-infected detained aliens repatriated to Mexico each year is useful for understanding the demand on ICE regarding care transition of detainees repatriated to Mexico. It averages to 2-3 repatriations of HIV-infected Mexican aliens every two weeks.

### **Qualitative Study**

This section reports the results of telephone interviews conducted with nine key informants, as shown in Table 8. The interviews lasted between 17 and 55 minutes (averaging 32 minutes). The key informants possessed an average of 15 years of experience working on aspects of HIV and/or TB care transition between the United States and Mexico (range 8-35 years).

**Table 8. Sector and Frequency of the Nine Key Informants** 

Sector	Frequency
Academia	1
Local health department (county, regional)	2
Non-governmental organizations	2
Clinical practice	2
State health department	2

This qualitative study used a convenience sample limited to nine key informants. In total, 17 individuals were approached to participate as key informants in this study. All key informants were U.S.-based. Of the eight individuals who were approached but did not participate, two did not respond; two were not available to participate in the timeframe requested; three declined to participate citing a lack of expertise in the topics to be covered in the interview; and one declined to participate for other reasons. The U.S. and Mexican federal government perspectives were not represented. Due to the small number of key informants, the results were not generalizable, they were exploratory and limited to the experienced and perceptions of those interviewed. It is possible that due to the limit of key informants, some viewpoints were inadvertently omitted.

The content of each key informant interview transcript was coded using NVivo. A priori codes were created based on the interview questions—organized by the research aim. Themes

are the outcomes of the coding process, as described in Chapter 3 (Methods), and are defined as the suggested solutions to the research question of how to improve HIV care transition for detained aliens repatriated to Mexico by ICE. Concept tables were used to outline the relationship between the research question and research aims, with primary and sub-themes from the key informant interviews (see Tables 10-12). The results were organized by the three research aims, or questions, and then within each research question, by suggestions for improvement (i.e., theme). For each theme, vignettes from the individual interviews were included as they supported the key themes and resulting conclusions. A total of seven themes emerged from the coding process and are described herein, and presented in Table 9, as "areas for improvement" in the HIV care transition process for repatriated Mexican aliens. A summary of the suggestions from key informants is also included in Table 9 and organized by theme.

Table 9. Areas for Improvement (Themes) and Summaries of Suggestions from Key Informant Interviews

Areas for Improvement (Themes)	Summary of Suggestions from Informants
Access to HIV services in Mexico	Ensure repatriated HIV-infected aliens can access HIV health services in Mexico by ensuring they have a federal identification number and addressing how to travel to/from health services
Coordination between ICE and U.S. and Mexican health authorities for the repatriation of HIV-infected aliens	Ensure U.S. and Mexican health authorities are included in the removal of HIV-infected aliens in ICE custody; the health authorities have processes to provide detainees HIV care transition
Binational exchange of HIV medical records	Address three challenges for U.SMexico HIV medical record sharing: access, confidentiality, and patient consent
ICE procedures for HIV care transition	Educate ICE clinicians on how to connect HIV-infected aliens to care in Mexico
Education of HIV-infected aliens in ICE detention	Educate HIV-infected detainees in ICE facilities on the importance of continuing care and treatment and how to access HIV care services in Mexico
Binational agreement(s) for the exchange of data and medical records	Establish data and medical record sharing agreement(s) and ensure that the appropriate levels of government (local, state, and federal) from the United States and Mexico are informing and driving their development
ICE detention standard for HIV care transition	Implement ICE's detention standard for HIV care transition for removed aliens (i.e., provide HIV/AIDS medication, referrals to providers, and a medical care summary)

#### Qualitative Results for Aim #1

To answer aim #1, key informants were asked two questions about the current situation for HIV care transition of detained aliens with responses, presented in Table 10. Two themes emerged from their responses: 1) access to HIV services in Mexico and 2) binational coordination during repatriation, explored in more detail herein.

## Table 10. Qualitative Results for Research Aim #1

Aim #1: Explore how various stakeholders perceive the current quality of HIV care transition for detained, HIV-infected aliens removed from the United States to Mexico.

#### **Interview questions:**

• How would you describe the current situation regarding the access detained HIV-infected aliens have to continued HIV care and treatment in Mexico upon arrival?

<ul> <li>continued HIV care and treatment in Mexico upon arrival?</li> <li>How would you characterize the coordination of HIV care transition between U.S. and Mexican authorities?</li> </ul>			
Emerging			Example Quote
Themes	Themes	,	Zamapie Queet
Access to		Availability and accessibility	
HIV		of HIV health services in	
services in		Mexico	"The Country of Color of the HIV
Mexico	HIV/AIDS health care delivery	All Mexican citizens have a right to health care, including access to HIV/AIDS treatment, which is subsidized	"The Secretaria de Salud operates an HIV program known as CAPASITS. Most of the major municipalities in Mexico along the border have these CAPASITS. So, if a person ends up on the Mexican side and they're HIV-positive and under treatment, they can go to the CAPASITS and receive their care, at no cost."
	Mexican federal ID	To access Mexico's public health system, the Mexican federal ID #, the CURP (Clave Única de Registro de Población), is needed	"As soon as somebody is deported through the port- of-entry, they have to pass through Mexican immigration. So, at that point, they must prove their Mexican citizenship, and then once they're in Mexico they don't have to show a card or anything when they go to the CAPASITS. Their federal ID number is already in the system."
	HIV/AIDS treatment	Through the CAPASITS, HIV/AIDS treatment is available; the medications provided are on par with those available in the United States  A logistical challenge for	"Access to resources regarding HIV and AIDS treatment is being facilitated by the Mexican government through the CAPASITS. So, Mexican doctors have resources, they have medications, and they feel confident when receiving cases. Nearly all HIV medications available in the United States are now available to in Mexico."
	accessing health care	HIV-infected repatriated aliens is transport to care	"How do you even get to a CAPASITS when you're deported? Accessing the health care in Mexico is a main challenge. I mean physically accessing it."
Binational coordinatio n during repatriation		U.S. and Mexican health authorities have processes for HIV care transition for detainees—if they are included by ICE in the removal	"When we know that we have somebody who's HIV-positive, then the coordination of care is very high. We have systems in place with our Mexican health counterparts that can be used to facilitate a proper medical handover to Mexican health authorities, we just need to be notified and included in the removal process by ICE."

### Emerging Theme #1: Access to HIV Services in Mexico

Key informants spoke about Mexico's national policy on HIV treatment that has been providing universal access to ART through the national health system since 2003 (UNAIDS, 2017). According to the national policy, all Mexican citizens have a right to health care. To access HIV care, the repatriated alien will need to be in the Mexican immigration system and/or otherwise have access to their CURP number, which is their federal ID number. Through the CAPASITS, HIV/AIDS treatment is available and on par with those available in the United States. The challenge facing repatriated HIV-infected aliens is how to physically access the CAPASITS as reported by one physician during the interview:

So, what we encounter nowadays is that, for example, immigrants come to the U.S.-Mexico border, they apply for a [U.S.] visa, and they get their medical exam done. And if they admit that they have HIV we are supposed to collect smears and cultures for tuberculosis. And they must wait in Mexico for at least eight weeks, which is how long it takes to find out if the tuberculosis culture is negative. So, they encounter a lot of problems because they do not arrive with enough HIV medication for eight weeks and so we need to refer them to the health centers, CAPASITS, in Mexico. So that's why I know that HIV treatment is available because it is not difficult for me to call a health center and tell them like, "Hey, we have an HIV patient and he's going to be traveling through your jurisdiction to ask for HIV treatment." And they will usually get the medicine. So, the access is easy.

For repatriated HIV-infected Mexican aliens, HIV/AIDS treatment is readily available. The challenge is in accessing the physical CAPASIT location. If the repatriated alien is not met at the port-of-entry by a health official, it is hard to know where CAPASITS are located or how to get to one without money. This observation was expressed by one non-government organization (NGO) official as follows:

I know there is a national number that HIV-infected deportees can call to find the closest provider. It's run by the Mexican federal agency in charge of HIV treatment and prevention. But this is an inherent challenge as, uh, if you are deported to Mexico and have nothing, how will you make this call? Ideally, the linkage to the treatment facility would happen before the individual arrives in Mexico.

### Emerging Theme #2: Binational Coordination during Repatriation

Key informants spoke about how U.S. and Mexican health authorities have processes in place that they can use for HIV care transition for detainees—provided the health authorities from the United States and Mexico are included by ICE in the removal process. The missing link reported by the key informants was for county and/or state health officials to be notified by ICE (by telephone or e-mail) with enough advance notice to arrange care transition with Mexican health officials. The U.S. state or county health officials would provide information to the Mexican health authorities about the HIV-infected Mexican alien and link them directly with the alien during ICE removal. The onus appears to not be on ICE to arrange the care transition, the U.S. state and local health departments will do that. What is needed is for ICE to provide that advance notification as noted by one state official as follows:

Having authorities involved at both sides of the border is very effective. For example, the person in charge of the health program or the HIV program in El Paso, Texas, for example, has the ability to communicate with the head of the HIV program in Juarez, Mexico. So just, I mean...by having a good coordination they might, you know, alert the person in charge in Mexico like, "There's going to be a patient returning to Mexico through this boarder location and he's under this medication. He has been diagnosed on this date," all the clinical information. So, the actual head of the Mexican HIV program can receive that patient and then just continue the treatment where it was left. So that's something that I would consider successful, bringing all the stakeholders involved on HIV care together and work in that same effort.

#### Qualitative Results for Research Aim #2

To answer aim #2, key informants were asked three questions about the current coordination and cooperation for HIV care transition of detained aliens as well as main challenges and administrative barriers. Three themes emerged from their responses: 1) binational exchange of medical records, 2) ICE procedures for HIV care transition, and 3) educating HIV-infected aliens in ICE detention before removal. The investigator explored these three emerging themes in more detail, as shown in Table 11.

# Table 11. Qualitative Results for Research Aim #2

Aim #2: Identify some of the challenges affecting HIV care transition for detained, HIV-infected aliens removed from the United States to Mexico

### **Interview questions:**

- How would you characterize the coordination of HIV care transition between U.S. and Mexican authorities? How could this cooperation be improved?
- What are the most important administrative barriers for HIV-infected aliens to access HIV care and treatment in Mexico?

• What are the main challenges for continuity of HIV care and treatment in this population?

	• What are the main challenges for continuity of HIV care and treatment in this population?			
Emerging Themes	Sub-Themes	Summary	Example Quote	
Binational exchange of HIV medical records		Challenges for binational HIV clinical record sharing include access, confidentiality, and patient consent concerns		
	Access to medical records	A challenge for timely HIV care transition is access to U.S. medical records	"Those who are deported don't have their medical records, but the clinician in Mexico needs it to continue the correct treatment. We need to figure out a way to get the medical records from ICE, from U.S. clinicians, to Mexico."	
	Patient confidentiality	There are barriers to securely sharing HIV patient records between U.S. and Mexican authorities and health care providers	"One huge barrier that I see on communication is HIPAA compliance. In the U.S. it's very strict, but we don't use it in Mexico. Sharing a person's sensitive health information through encrypted emails is not accessible for Mexican clinicians, either because their computer system doesn't recognize those e-mails, or they are not familiar with it."	
	Patient consent	ICE requires patient consent to release medical records, any delays in getting consent impact the timely sharing of clinical information with Mexican health authorities	"When people bring up patient privacy concerns and consent to release, I say, 'Well, to me that would be fairly easily resolved.' You know the person's in ICE custody, and it should be one of the forms that they should be signing before removal. I don't know if- if that is done."	
ICE procedure s for HIV care transition		Binational continuity of HIV care for detained aliens requires coordination between U.S. and Mexican health authorities and ICE clinicians		

	Coordinating medical handover to Mexico	Advance notification from ICE to U.S. health authorities to coordinate with Mexican health authorities for the removal of aliens to Mexico	"No uniform system exists to inform state and local HIV programs when a person under ICE care who has HIV is going to be deported or released. But repatriation should not take place until the necessary arrangements with the Mexican health authorities are made."
	Educating ICE clinicians	Importance of training ICE clinicians about why connecting patients to care in Mexico is important and process(es) to do so	"The primary mission of ICE is law enforcement, and the public health side is like the ugly stepchild. We mainly see this with complicated cases, where we're hoping that ICE could hold onto somebody long enough for us to get the infrastructure in place on the Mexican side to do the care transition. And there's pushback because, from the law enforcement side, they're wanting to remove the person. So, what we need to do is spend the time to educate ICE staff about why care transition is so important."
Educating HIV-infected aliens in ICE detention before removal		Need for routine education of HIV-positive detainees in ICE facilities on the importance of continuing care and treatment and where to access services	"With diseases such as HIV—80% of the success of the outcome is on the patient and 20% is on the clinician. If I were deported, for me to know, number one, that a CAPASITS exists, and then, how do I get there if I don't have any money in my pocket. And so, an administrative barrier is educating the HIV-positive detainees in ICE facilities."

### Emerging Theme #3: Binational exchange of HIV medical records

Key informants identified challenges for binational HIV clinical record, which included access, confidentiality, and patient consent concerns. Most key informants spoke about the need for timely access to medical records to facilitate care transition. They also mentioned the subtheme of privacy concerns as well as differences in how U.S. and Mexican health care practitioners handle sensitive information sharing—which is a barrier inhibiting the ability to share clinical history between the two countries. One way to address the privacy concerns is to ensure that the detained alien signs a consent form to release their medical records to Mexican health authorities, but uncertainty exists about whether this is currently being done in ICE detention. This concern was reflected in one local health official's response:

So, when an HIV-positive patient shows up at the CAPSITS, you can imagine if somebody who's been under HIV treatment for several years, and they've had maybe a complicated clinical history, the doctors on the Mexican side don't have that clinical information. And if the patient doesn't remember the name and dosage of everything he or she is taking, then that's a real barrier right there for them to start up HIV treatment right away.

# Emerging Theme #4: ICE procedures for HIV care transition

Two sub-themes emerged in discussions about coordination gaps between U.S. state/local and ICE health officials and Mexican health officials. First, key informants spoke about the need for ICE officials to coordinate with other stakeholders *before* removing a Mexican alien who will need a medical handover. Without this referral from ICE to local and state health departments in the United States, there are limited opportunities for patient education pre-departure, and the possibility of unsuccessful HIV care transition increases. Second, key informants spoke about the need to provide trainings to ICE clinicians and staff regarding the public health concerns, and importance, related to effective care coordination. One state health official responded as follows:

So, with some ICE authorities, they don't share timely information regarding people that they are going to repatriate back to Mexico. For example, one of the challenges that exists is that when ICE is going to send back someone to Mexico, they do it randomly. For example, they will release a patient maybe at 2:00 in the morning at a specific bridge. And then that person has to cross the border at night and then just find their way in the border town because they were sent back with no Mexican health officials available to receive them, et cetera. So, if we improve communication and we have people coordinating the entry of these sick aliens back into Mexico, then it will be coordinated to have a clinician waiting to meet the patients. So, they'll be free from having to make it on the streets of Juarez and then, and then the next day they're in Tijuana or maybe somewhere else, and they already spread the disease. So, I think, I think that communication between everyone that is involved is crucial, beginning with ICE and then especially the Mexico and U.S. health authorities.

### Emerging Theme #5: Educating HIV-infected aliens in ICE detention before removal

Most key informants spoke about the need for routine education of HIV-positive detainees in ICE facilities regarding the importance of continuing care and treatment and where to access services. Given that the eventual success of the care transition rests on whether the

repatriated alien continues treatment, educating them about what HIV/AIDS is, how it is transmitted, why they should treat it, and how to access care is important. The key stakeholders who spoke about this theme underscored that the education should take place while the alien is in ICE detention and should not wait until they return to Mexico. One academic stated, "I think that education is crucial. I mean, the HIV-infected people being repatriated need to be aware of what to expect when they return so they can be prepared."

### Qualitative Results for Research Aim #3

In order to answer aim #3, key informants were asked four questions about the ideal HIV care transition process and lessons from TB care transition—or other models. Two themes emerged from their responses: 1) binational protocols and 2) ICE detention standards for medical care, represented in Table 12.

Table 12. Qualitative Results for Research Aim #3

Aim #3: Explore whether there are lessons from tuberculosis care transition for detained, TB-infected aliens removed from the United States to Mexico that can be applied to HIV care transition, and/or if there are other models that could inform the research question.

#### **Interview questions:**

- What would an ideal HIV care transition process look like to you?
- How would you describe the current situation regarding tuberculosis care transition for detained aliens removed to Mexico?
- What would an ideal TB care transition process look like to you?
- In addition to tuberculosis, are you aware of models of care transition in other settings that might provide insights on how to improve HIV care transition in this population?

Emerging Themes	Sub- Themes	Summary	Example Quote
Binational protocols	Data and medical record sharing agreements	Foster local, state, and federal collaboration between the United States and Mexico to improve providing information and organization for HIV care transition  Improve HIV clinical information sharing by using a binational platform	"As it relates to the actual care transition of a detained HIV-infected migrant, Mexico and the U.S. should establish international data and medical record sharing agreements, perhaps leveraging existing CureTB or Migrant Clinicians Network infrastructure and ensuring the sensitivity of the HIV data is addressed."

	Cross- border HIV referral program	Enable coordination amongst health authorities and providers in both countries to facilitate HIV health care access	"It's about the three C's. It's the communication, the coordination, and then the collaboration. And it has to be in that order. I mean, you have to start with communication, listening to our colleagues on the Mexican side. That allows us to then coordinate all the things that we're doing."
	Local, state, and federal binational coordination	Ensure the appropriate levels of government from the United States and Mexico are informing and driving the decision-making for any process developed	"If you try to do things only at a local level, um, they'll work for a little while, but then they're going to fail because it wasn't a policy change at a state level. Allowing the communication and coordination decisions to be made at the state, and then bringing those decisions to the local level, you're ensuring that the process is going to happen, is going to live on."  "Part of the reason of the success in Arizona [for TB]
	of state and local context	For a protocol or model to be effective, it will need to work within the state and local situation	care transition] is that the overall volume of ICE detainees in Arizona isn't huge. So, it's not like San Diego's San Ysidro port of entry, or El Paso's."
ICE Detention Standards for Medical Care		Implement ICE's HIV care transition guidance for removed aliens (provide HIV/AIDS medication, referrals to providers, and a medical care summary)	"The ideal scenario is that if somebody's being deported and has HIV, that those removals would happen the right way. And so, when we know that an ICE detainee is HIV-positive, we know that he or she is on treatment, that, prior to his or her removal date or removal date, the state health authorities would be notified, and we would coordinate with Mexico on the health transition. It is our job to do that coordination, it should not be a burden on ICE."

Emerging Theme #6: Binational Protocols. Most key informants spoke about the need to foster local, state, and federal collaboration between the United States and Mexico to improve the ability to provide information and organization for HIV care transition of detained aliens. The most important sub-theme key informants mentioned was the need for data and medical record sharing agreements. Most of the key informants spoke about ensuring that the Mexican Secretariat of Health perspective is an integral part of any created process. Several key informants underscored the need to create the protocols at the state and/or local level, highlighting the diversity in state and local regulations and protocols for how to engage with Mexico. However, this diversity could mean instead that uniform federal standards would be easier, especially as ICE is a key player and local protocols would mean that ICE would have to

deal with many different jurisdictions and bureaucratic entities. One state health official affirmed by stating the following:

And uh, and so now the way we've approached it, we've made sure that we're working with the Mexican Ministry of Health, that they know what's going on, that the Mexican state HIV program director is involved in all the decisions. And it's working a lot better. We need that buy-in from our Mexican colleagues. Mexico has to be an integral part of the solution ... You know, understanding the differences in our health systems, understanding the hierarchy differences on the Mexican side, that on the U.S. side sometimes we just don't get. Or we don't pay attention to the importance of it.

Emerging Theme #7: ICE Detention Standards for Medical Care. Several key informants spoke about the need to implement ICE's HIV care transition guidance for removed aliens, which is in their detention standards. The HIV care transition guidance includes the provision of 30-days of HIV/AIDS medication, referral(s) to providers, and a printed out medical care summary. If ICE were routinely providing these items, the HIV care transition process could improve. One NCO official noted, "The transnational continuity of HIV care is complex and creating a robust public health approach to it will require political will from the United States and Mexico."

#### **Discussion**

### How the Analysis Ties Back to the Primary Research Question

The research sought to answer the question: How can HIV care transition be improved when ICE repatriates detained aliens to Mexico? The results from the key informant interviews and secondary data analysis explored perceptions of the current quality of HIV care transition, identified challenges with the care transition process, and explored lessons from other programs (TB) that could inform the HIV care transition process. The secondary data analysis found that while under-reported, ICE is repatriating an average of 2-3 HIV-infected aliens to Mexico every two weeks. This estimate is useful for assessing the demand on ICE for HIV care transition for

HIV-infected detainees repatriated to Mexico. ICE detention standards (ICE, 2011, 2019) state that ICE will provide aliens with three things upon repatriation: 1) medical care summary, 2) 30day supply of HIV/AIDS medication, and 3) referrals to providers. These standards for HIV care transition are not routinely implemented. Because this study did not include the federal government (ICE) perspective, it is unclear why the standards are not taking place. Exploring why they are not happening is a potential area for future research (see Recommendations for future research below). Key informants underscored that U.S. and Mexican health authorities have created state and local protocols to link HIV-infected aliens leaving the United States with HIV/AIDS care services in Mexico. These protocols include getting relevant medical history from ICE and sharing it with Mexican health officials, coordinating on a time and location for the repatriation so that there is a Mexican health official present to meet the alien upon removal and provide him/her with linkage to care in Mexico. Several key informants mentioned that if ICE did bring in the U.S. health authorities regarding removals of HIV-infected aliens, the health authorities could facilitate confirming the date and time for the removal and could take responsibility for the care transition itself—alleviating ICE of needing to oversee the care transition process.

While removed HIV-infected aliens should have their medical care summary (which includes the necessary treatment information that Mexican clinicians will need), in the long-term, most key informants spoke about the need for more formal binational coordination at all levels of government (federal, state, local), across both ICE and health authorities, in both countries. Most key informants recommended formal data and medical sharing records agreements that address issues of access, confidentiality, and patient consent.

### **Study Limitations**

This study entailed a number of limitations. First, the exclusive reliance on Englishlanguage studies in Chapter 2 (Literature Review) may mean that not all the evidence available was represented regarding HIV and/or TB care delivery within the immigration detention system in the United States and/or care transition upon removal to an alien's country of citizenship. Second, a possible limitation of the qualitative study was that it was limited to nine key stakeholders. (Note: UNC advises students to limit key informant interviews to nine as Office of Management and Budget [OMB] clearance is not required for fewer than ten participants.). When fewer than 15 people are interviewed, it can be difficult to demonstrate the validity of the findings. Although the number of key informant interviews was low, the results confirmed many of the literature findings, indicating there are enduring challenges for HIV care transition that are not likely to dissipate without intervention. Third, the investigator could have introduced bias into the coding of the qualitative interviews because interpretation of the findings could have been unavoidably shaped by their background, female gender, culture, history, and socioeconomic origin (Creswell & Creswell, 2018). To address this bias, interviewees were asked to review, affirm, or modify transcripts of their interviews. The investigator also worked with a second coder to interpret themes and reconcile the findings. Fourth, the key informants may have misclassified their responses or interpreted the questions through their own personal lenses and experiences, even though the investigator reviewed definitions of terms at the beginning of the telephone interview. In some cases, survey respondents were not able to answer all the questions due to tenure, experience, or involvement in only a particular aspect of the work. Fifth, the lack of patient perspective(s) (i.e., the voice of the HIV-infected Mexican alien repatriated to Mexico by ICE) was an important limitation of this exploratory research. It is

important to understand from their perspective what factors contribute to successful HIV care transition. However, directly interviewing the aliens was outside the scope of this exploratory research study. Sixth, the results of the mixed methods exploratory research suggested that even while under-reported, the number of HIV-infected aliens repatriated to Mexico is not insignificant (average of 2-3 removals of HIV-infected aliens every two weeks).

#### **Recommendations for Future Research**

Based on the results of this mixed methods study, recommendations for future research included the following: 1) learning more about the challenges and opportunities for implementing ICE detention standards (ICE, 2011, 2019) that govern what to provide HIV-infected detained aliens upon release into the United States/repatriation to the country of citizenship (i.e., medical care summary, referral to community providers, 30-day supply of medicine); 2) more accurately measuring the prevalence of HIV/AIDS in Mexican aliens detained by ICE and the prevalence in the population of ICE detainees repatriated to Mexico; 3) analyzing the outcomes of HIV-infected detained aliens linked to continued HIV/AIDS care in Mexico (e.g., ART adherence) and examining factors contributing to successful outcomes and those inhibiting success (e.g., stigma, CAPASIT access); 4) prospectively researching the impact that Mexico's new health care scheme (INSABI), introduced January 2020, will have, or not have, on HIV treatment access for repatriated HIV-infected aliens; and 5) exploring ways to increase HIV testing in ICE facilities as well as unintended outcomes of increased testing/changes in the ICE HIV testing protocol.

#### Conclusion

ICE is repatriating an estimated 2-3 HIV-infected Mexican aliens every two weeks.

According to the key informant interview results, opportunities exist to enhance HIV care

transition for these HIV-infected aliens upon repatriation to Mexico. Opportunities on the front-end—while the HIV-infected aliens are in ICE custody—include the following: 1) educating HIV-positive ICE detainees about HIV/AIDS, the importance of treatment adherence, and how to access HIV services in Mexico upon repatriation and 2) educating ICE clinicians about how to connect HIV-infected detainees to care when they are repatriated to Mexico.

Opportunities to improve the care transition process for HIV-infected ICE detainees included the following: 1) implementing the ICE detention standard for HIV care transition by repatriating HIV-infected aliens with a 30-day supply of medication, a copy of their medical care summary, and a referral to a community provider in Mexico and 2) having ICE coordinate with U.S. local and/or state health authorities before removing an HIV-infected alien so that the U.S. health authority can coordinate with their Mexican counterparts to have someone meet the alien upon arrival to Mexico and ensure care transition takes place.

Post-repatriation opportunities to improve access to HIV/AIDS care and treatment that this research identified included the following: 1) addressing stigmatization (identified in the literature review in Chapter 2); 2) ensuring each repatriated alien has their CURP number (Mexican federal ID # or the "Clave Unica de Registro de Población"); 3) addressing the challenge of access to a CAPASITS for care and treatment (i.e., physical distance, lack of money to pay for transportation there); and 4) providing Mexican clinicians with HIV medical records/history to continue effective and proper treatment (e.g., binational challenges including privacy concerns, patient consent, as well as the lack of access to ICE medical records).

Finally, creating binational protocol(s) for the exchange of medical records/clinical information, coupled with the implementation of an HIV care transition program—possibly modeled after CureTB—could potentially address many of the identified barriers for care transition. This proposal generated by input from key stakeholder interviews was included in the policy options considered in Chapter 5 (Policy Analysis).

Table 13. Summary of Key Themes and Suggested Solutions from Key Informant Interviews

# Theme #1: Access to HIV services in Mexico

- Ensure HIV-infected aliens have a Mexican federal identification number
- Address the challenge of how to physically access HIV care and treatment services

# Theme #2: Coordination between ICE and U.S. and Mexican health authorities for the repatriation of HIV-infected aliens

• Ensure that U.S. and Mexican health authorities are notified in advance about the removal of an HIV-infected alien in ICE custody as they can arrange for the care transition of the alien (i.e., ensure a Mexican health representative meets the alien at the border to escort them through their linkage to HIV care and treatment)

# Theme #3: Binational exchange of HIV medical records

• Address three challenges for U.S.-Mexico medical record sharing: access, ensuring confidentiality, and patient consent

# Theme #4: ICE procedures for HIV care transition

• Educate ICE clinicians about how to connect HIV-infected aliens to care in Mexico

### Theme #5: Education of HIV-infected aliens in ICE detention

• Educate HIV-infected detainees in ICE facilities on the importance of continuing care and treatment, and about how HIV care services operate in Mexico

### Theme #6: Binational agreement(s) for the exchange of data and medical records

• Establish data and medical record sharing agreement(s) and ensure that the appropriate levels of government (local, state, federal) from the United States and Mexico are informing and driving their development

# Theme #7: ICE detention standard for HIV care transition

• Implement ICE's detention standard for HIV care transition for removed aliens (i.e., provide HIV/AIDS medication, referrals to providers, and a medical care summary)

### **CHAPTER 5: POLICY ANALYSIS**

This chapter considers policy options to address the primary research question: How can HIV care transition be improved when U.S. Immigration and Customs Enforcement repatriates detained aliens to Mexico? The policy options are based on the results of Chapter 4. Policy analysis is the process of identifying potential policy options, ranking each one based on defined criteria, and selecting the final policy option to pursue. The results of this policy analysis are used in Chapter 6 (Plan for Change), which focuses on creating a plan to actualize the selected policy option.

### Methodology

This policy analysis was based on Bardach's eightfold path (Bardach & Patashnik, 2015). Bardach's eight steps for policy analysis—which echo to a large extent the steps taken in this dissertation—are as follows:

- 1) **Define the problem (needs statement):** Define the problem's magnitude.
- 2) **Gather background evidence:** Describe the gaps, key players, existing resources, and identify policies/programs that have been tried in other places to address the same or similar problem.
- 3) **Construct alternatives:** Brainstorm a list of possible strategies (policy options) to address the problem and include the "status quo" as one of the options; strategies can be combined to form a policy option.

- 4) **Select the criteria to evaluate the policy options:** Define the criteria; include three criteria: cost to implement, political feasibility, and impact. Consider whether to weight each criterion differently.
- 5) **Project the outcomes:** Evaluate each policy option against the criteria; incorporate qualitative information or quantitative (cost-benefit, modeling) methodology to evaluate the options; and consider the minimum level of effectiveness the policy needs to have to justify the expenditure/change and recognize the difference between economically/technically feasible and politically acceptable alternatives.
- 6) **Confront trade-offs:** Consider the outcomes of each policy option.
- 7) **Decide:** Identify the strongest option.
- 8) **Tell the story:** Explain the problem and potential solutions (i.e., write this chapter and the plan for change in Chapter 6).

This chapter (Policy Analysis) focuses on Bardach's steps 3-8. The following sections describe the evaluation criteria and policy options selected for this policy analysis. The concluding section of this chapter describes limitations to this policy analysis.

### **Policy Options**

To strengthen the care transition for HIV-infected aliens removed by ICE from the United States to Mexico, this policy analysis evaluated the following five policy options—two of which are combinations of policy options: (1) repatriate without support (maintain the status quo); (2) repatriate with a supply of medication (provide HIV-infected aliens with a 90-day supply of ART upon removal); (3) repatriate with ICE medical care summary; (4) repatriate with community-based provider referral, ICE medical care summary, and a supply of medication (inline with current ICE detention standards); and (5) repatriate with community-based provider

referral, ICE medical care summary, and a supply of medication and binational data sharing.

This fifth option was in-line with ICE detention standards for repatriation of HIV-infected aliens and would also include creating a binational platform for the sharing of data and medical records.

These policy options reflect the key informant suggestions identified in Chapter 4 for ways to improve HIV care transition for detained aliens repatriated to Mexico.

### **Evaluation Criteria**

The "proposals (or "policies") stream" in Kingdon's (1984, 1995) MSF refers to the "soup," which consists of a multitude of policy proposals. Many proposals may exist that attempt to address the same problem. To make it to the "shortlist," each policy option was evaluated by five standard criteria: 1) cost to the U.S. federal government to implement; 2) the impact on improved binational HIV care transition; 3) the political feasibility of being adopted; 4) the ease of operational implementation; and 5) the impact on the health of the HIV-infected alien being removed. Four of these criteria reflected Bardach's guidance on what to evaluate (Bardach & Patashnik, 2015): cost to the government to implement, political feasibility, health impact in the long-term (improved binational HIV care transition), and health impact in the short-term (impact on the health of the HIV-infected alien being removed). The additional criterion—ease of operational implementation—was selected to capture in the ranking the practicality of the policy options. How difficult is it to operationalize/put into use the policy option? Each assessment criterion was ranked from 1 (least meets the evaluation objective) to 5 (most meets the evaluation objective). To assess the cost of potential policy alternatives, the investigator examined affordability from the U.S. federal government's perspective, such that a 5 indicated the most affordable option for the government and 1 indicated the costliest option, requiring a significant budget appropriation from Congress or the reprogramming of agency

funds. Impact refers to the magnitude to which a policy option will effectively lead to HIV-infected aliens removed to Mexico being successfully linked to continued care and treatment. This systems-level criterion has the potential to positively influence the number of HIV-infected aliens removed to Mexico who are successfully linked to continued HIV care. Therefore, this measure was given twice the weight. Political feasibility denotes the probability of a policy option successfully being enacted either through the legislative or regulatory process. Ease of operational implementation is a measurement of the ability of the U.S. Department of Homeland Security to implement the policy option. The immediate impact on the health of the HIV-infected alien being removed refers to the magnitude to which a policy option will ensure that there is no HIV treatment interruption for an individual alien. Higher scores relate to lower risk of treatment interruption. This individual-level criterion has the potential to positively influence the number of HIV-infected aliens removed to Mexico who are successfully linked to continued HIV care. Therefore, this measure was given twice the weight.

# **Policy Assessment**

The results of the policy analysis are described herein. Table 14 visually shows the rankings of the five policy options against the five evaluation criteria. The rationale for the ranking for each option is described below, by policy option. The end of this chapter presents a short discussion of the highest-ranked policy option(s). Chapter 6 (Plan for Change) explores the plan for actualizing the highest-ranked policy option(s).

Table 14. Ranking of the Various Policy Options for Improving HIV Care Transition for Aliens Repatriated to Mexico by U.S. ICE

Evaluation Criteria	Policy 1: Repatriate without support	Policy 2: Repatriate with a supply of medication	Policy 3: Repatriate with ICE medical care summary	Policy 4: Repatriate with community- based provider referral, ICE medical care summary, and a supply of medication	Policy 5: Repatriate with community-based provider referral, ICE medical care summary, and a supply of medication; binational data sharing
Affordability: Lowest cost to the federal government to implement 1=Costliest 5=Most affordable	++++	+++	++++	+++	++
Impact on improved binational HIV care transition (weighted *2) 1=Little impact 5=High Impact	+	++	++	+++	++++
Political feasibility of being adopted l=Unlikely 5=Likely	++++	++	++++	+++	++
Ease of operational implementation 1=Not easy 5=Easy	+++++	++++	++++	+++	++
Impact on the health of the HIV-infected alien being removed (weighted *2)  1=Limited positive impact 5=High positive impact	+	++++	+++	++++	++++
Overall Ranking *	19	21	22	23	26

<sup>\*</sup>The overall ranking represents the summary of the evaluation criteria scores; the rankings for *impact on improved* binational HIV care transition and impact on the health of the HIV-infected alien being removed were weighted \*2.

# Policy Option #1: Repatriate without Support (Maintain the Status Quo)

If no additional steps are taken to improve care transition for HIV-infected aliens repatriated to Mexico, then the developing HIV epidemic at the U.S.-Mexico border will continue to grow. As mentioned in Chapter 1, in Mexico, a large proportion of the country's HIV infection has been associated with migration *from* the United States. Enhanced U.S. immigration enforcement and removal policies are leading to an increasing number of repatriations each year which, based on the estimate from Chapter 4 (Results and Discussion) of 2-3 repatriations of HIV-infected aliens every two weeks, could lead to hundreds of HIV-infected individuals at risk of treatment interruption, poor health outcomes, and ongoing transmission in receiving communities and at the border between Mexico and the United States each year. Ensuring uninterrupted HIV treatment is so critical to both the alien's health and to prevent transmission in the community.

- Affordability (5/5) Given that no HIV care transition steps are taken under the status quo,
  no additional costs will be incurred, and no funds will need to be allocate by ICE or U.S. and
  Mexican public health authorities.
- Impact on HIV care transition (1/5) Given the absence of HIV care transition steps under the status quo, there is, therefore, no impact on improved binational care transition.
- **Political feasibility (5/5)** As no HIV care transition action will be pursued under the status quo, traditional political measures taken to support policy will be employed.
- Ease of implementation (5/5) Under the status quo, there is no policy/action to implement.

  The status quo only requires continued maintenance of current ad hoc HIV care transition efforts.

• Impact on the health of the HIV-infected alien being removed (1/5) – Under the status quo, there is a high risk of HIV treatment interruption and, therefore, poor health outcomes for the alien being repatriated to Mexico.

# Policy Option #2: Repatriate with a Supply of Medication

This policy option proposes to provide a 90-day supply of ART to HIV-infected aliens repatriated to Mexico by ICE. The current ICE detention standard is to provide a 30-day supply. Continued and consistent access to ART after repatriation to Mexico will help ensure continued viral suppression. In contrast, the repatriation alien takes steps to acclimate to Mexico, including accessing their Mexican federal ID number, known as the CURP (Clave Única de Registro de Población). The CURP is needed to receive health care under Mexico's health program INSABI. INSABI is designed to provide comprehensive coverage for everyone, at any hospital or clinic belonging to Mexico's public health system, at no cost to the patient. All medications are covered, including ART. Because a Mexican federal ID number (CURP) can be a challenge to receive as it requires proof of residential address, and because most return migrants to Mexico are more focused on securing employment than accessing health care, providing a 90-day supply of ART provides extra security for treatment continuation during the period immediately post-repatriation.

• Affordability (3/5) – The average cost in the United States for a one-month supply of ART is roughly \$1,000 (Farnham et al., 2018). Based on the estimate of 63 HIV-infected aliens repatriated by ICE in FY 2018 (see Chapter 4, Results and Discussions), the additional cost to ICE to provide an additional 60-day supply of ART to all repatriated aliens is ~ \$126,000. While not insignificant an amount, this sum represents 0.0002% of ICE's total FY 2019 enacted budget of \$7.6 billion.

- Impact on HIV care transition (2/5) This policy option will have minimal impact on improved HIV care transition because it is time-limited, and it does not improve upon/ensure linkage to HIV care after arrival in Mexico.
- Political feasibility (2/5) Because ICE is already required to provide HIV-infected aliens
  with a 30-day supply of ART upon removal, there is little political incentive for ICE to
  provide an additional 60-day ART supply to the alien to ensure they are covered once in
  Mexico.
- Ease of implementation (4/5) Because ICE should already have a system in place for providing HIV-infected aliens with a 30-day supply of ART upon removal, the addition of 60 days of treatment should be relatively simple to implement.
- Impact on the health of the HIV-infected alien being removed (4/5) This policy option lowers the risk of HIV treatment interruption while efforts are made to ensure the alien has access to health services in Mexico.

# Policy Option #3: Repatriate with ICE Medical Care Summary

Mexican providers are often uncomfortable prescribing ART without previous medical records. As described in previous chapters, HIV-infected aliens removed to Mexico are not being repatriated with their medical records and/or medical care summary from when they were in ICE detention. Without access to previous medical records (including drug resistance profiles), health care providers in Mexico might make inadequate changes to drug regimens of aliens with drug-resistant HIV. Mexican citizens must provide certain documents to be able to receive HIV medications in Mexico, including a positive HIV antibody test result. For a repatriated alien, having access to their medical care summary could help facilitate a smoother transition to receiving HIV care in Mexico. This policy option would help to address the concerns outlined

and potentially make the linkage to care more efficient—at little cost to ICE. However, this policy option could place the burden on the alien to safekeep the physical medical care summary document during the removal process, which could be challenging and is a reason why policy option #5 provided herein is proposed.

- Affordability (4/5) This policy option would have limited additional costs to ICE as it involves providing each HIV-infected alien being repatriated to Mexico with a printed-out copy of their medical care summary, something ICE is required to do in its detention standard for HIV repatriation. The cost would be the limited staff time needed to compile and print the information.
- Impact on HIV care transition (2/5) This policy option will have a minimal impact on improved HIV care transition overall because access to medical records does not, in and of itself, enhance the linkage to care upon arrival to Mexico. What this policy will improve within the care transition process is the ability of the HIV-infected alien to receive treatment once connected with health services/CAPASIT.
- Political feasibility (4/5) This operational policy option is very low-cost and compelling because ICE is already required to provide HIV-infected aliens with medical care summary upon removal.
- Ease of implementation (4/5) Because ICE should already have a system in place to provide each HIV-infected alien with a medical care summary upon removal, this policy option should be relatively easy to implement.
- Impact on the health of the HIV-infected alien being removed (3/5) While a medical care summary will help ensure the HIV-infected alien receives appropriate treatment in Mexico, this policy option would have a mixed effect on the health of the alien because the

alien will still need to be linked to care in order for the care summary to be able to impact the health of the HIV-infected alien.

Policy Option #4: Repatriate with Community-based Provider Referral, ICE Medical Care
Summary, and a Supply of Medication

This policy option, which builds upon policy options #2 and #3, would have ICE implement its detention standard for the release/removal of HIV-infected aliens: "Detainee will be provided medication (a 30-day supply for HIV/AIDS), referrals to community-based providers, and a medical care summary" (NDS, 2019 & PBDNS, 2011). As established in previous chapters, this detention standard is not currently being implemented with regularity.

- Affordability (3/5) While this policy is already a requirement of ICE, it is not currently being implemented, which would mean there would be costs to beginning and maintaining its implementation—from staff time to compile and provide the medical summary and conduct the necessary outreach and research to be able to provide a provider referral in Mexico to pay for the 30 days of medication.
- Impact on HIV care transition (3/5) This policy option would have a mixed impact on the HIV care transition process. While it is the recommend "HIV care transition" provision for ICE, it does not include one very important component discussed in previous chapters—the need to physically meet the alien upon arrival and escort him/her to the CAPASIT and ensure the alien understands why continuing treatment is important.
- **Political feasibility (3/5)** Because ICE is already required to provide this policy option, it should not need political measures to ensure it is enacted. However, because this detention standard is not currently implemented, there will need to be support for this operational policy to ensure it happens.

- Ease of implementation (3/5) Because ICE is already required to provide this policy option, it should be easily implemented. However, because this detention standard is not currently implemented, there will be start-up costs in terms of staff time, training of staff, the purchase of medication, and other demands as the detention standard is operationalized.
- Impact on the health of the HIV-infected alien being removed (4/5) This policy option should positively impact the health of the HIV-infected alien by providing the removed alien with a supply of medication to help ensure there is not treatment interruption while the referral and care summary will help the alien access care and treatment.

Policy Option #5: Repatriate with Community-based Provider Referral, ICE Medical Care Summary, and a Supply of Medication; Binational Data Sharing

This policy option builds upon policy option #4 as it would have ICE implement its detention standard for the release/removal of HIV-infected aliens: "Detainee will be provided medication (a 30-day supply for HIV/AIDS), referrals to community-based providers, and a medical care summary" (NDS, 2019, & PBDNS, 2011). However, this policy option would also include the development and use of a legally and ethically sound online platform for sharing data/medical records to strengthen the coordination of HIV linkage to care for between the United States and Mexico. This platform would be complemented with a protocol governing how the platform is used, how the data is shared, and who has access to it. With these components combined, this policy could become a *U.S.-Mexico HIV/AIDS continuity of care program* focused on linking repatriated HIV-infected aliens with care services at their final destination—and ensuring all the necessary medical records/data reaches the providers. It would also include providing the alien with a 30-day supply of ART upon removal and engaging directly with the HIV-infected alien before repatriation (while in ICE detention) to educate them about their

disease and the importance of treatment adherence. Key informants identified available, instructive TB models in formulating such a care transition program. Two such examples are described later in this chapter. This policy option has the opportunity to have the largest impact on HIV care transition and on the health of the HIV-infected alien being repatriated, but it will be challenging to implement due to the cost, challenging to build political support, and would take much work to implement.

- Affordability (2/5) While aspects of this policy option are already a requirement of ICE for repatriation, none of the components of this policy option are currently happening.
   Consequently, there will be start-up costs and costs to maintain the program, including the online platform.
- Impact on HIV care transition (5/5) This policy option is focused on improving the HIV care transition process via the creation of a care transition program. For this reason, the impact of this policy option on HIV care transition is large.
- Political feasibility (2/5) Because the number of impacted aliens in ICE custody is small
  (N=63 across all ICE facilities, based on FY 2018 numbers) and the prevalence of HIV in
  Mexico is relatively low, the political support for creating a new program for HIV care
  transition may be limited.
- Ease of implementation (2/5) This is the policy option that will require the most effort to implement. In terms of operationally implementing this option, it will require a negotiated protocol between ICE and U.S. and Mexican health authorities about how the HIV care transition program will operate. The data-sharing platform will have to be built and managed. Additional staff may need to be hired by the U.S. and Mexican health authorities to ensure individuals are available to visit with and educate HIV-infected ICE detainees prior to

repatriation and to coordinate the actual care transition process. In regards to implementing the ICE detention standard—since ICE is already required to provide this policy option—it should be easily implemented. However, because this detention standard is not currently implemented, there will be start-up costs in terms of staff time, staff training, the purchase of medication, and other demands as the detention standard is operationalized.

• Impact on the health of the HIV-infected alien being removed (5/5) – This policy option would positively impact the health of the HIV-infected alien by providing the removed alien with all the identified components to support HIV care transition: education about the importance of continuing HIV treatment uninterrupted, linkage to care, a supply of medication, the provision of medical records to the clinician treating the alien, and enhanced coordination between ICE and U.S. and Mexican health authorities.

# **Policy Recommendations**

This policy analysis showed that the strongest option (i.e., highest scoring) for improving HIV care transition when ICE repatriates detained aliens to Mexico is to couple the creation and use of an online platform for sharing data/medical records with ensuring that HIV-infected aliens are repatriated with a copy of their care summary while in ICE detention, a referral to a provider for continued treatment, and a 30-day supply of HIV medication. One way to approach this policy proposal is to establish a U.S.-Mexico HIV/AIDS continuity of care program that would include creating a binational platform for sharing data and medical records; linking repatriated HIV-infected aliens with care services at their final destination in Mexico (and ensure they reach their final destination); providing the aliens with a 30-day supply of medication to ensure no treatment interruption occurs; engaging directly with HIV-infected aliens before repatriation (while in ICE detention) to educate them about their disease and the importance of treatment

adherence; and educating ICE clinicians about the importance of HIV care transition. Through the literature search (Chapter 2) and the key informant interview results (Chapter 4), two programs currently exist that can inform creating such a program: CureTB and the TB "Meet and Greet" Program. These two programs are described in more detail further.

Because of inherent challenges to implementing a U.S.-Mexico HIV/AIDS continuity of care program immediately (to be explored in depth in Chapter 6), a short-term step toward this longer-term policy goal is to pursue the next highest scoring policy option, which is to have ICE implement its standard for HIV care transition and provide all repatriated aliens with a copy of their ICE medical care summary, a 30-day supply of ART, and referral(s) to community-based providers. This policy option plays a critical role in ensuring HIV care transition and is a viable option politically because it is already an ICE detention standard, so it does not involve creating any new program. How best to pursue implementing the short- and long-term policy options will be explored further in Chapter 6.

# Program 1: CureTB

Established in 1997 within the TB Control Branch of the San Diego County Health and Human Services Agency, CureTB provides continuity of care for patients with TB who move out of the United States before completing treatment, including those removed by ICE (San Diego County Health and Human Services Agency, 2019). Although program operations transferred to U.S. CDC in 2016, CureTB retains a partnership with the San Diego County TB Control Branch.

CureTB functions as an information exchange and facilitation service for TB care transition. CureTB includes components of the selected policy option from the analysis conducted in this chapter—the program provides diagnostic and treatment history information to the receiving country's health officials and coordinates for TB care transition for the alien at the

point-of-arrival into their country of record. CureTB educates patients (including detained aliens prior to removal) about TB disease, the importance of treatment adherence, and how to access TB services. CureTB also has educated ICE clinicians about the importance of care transition. What is less clear is how CureTB's data platform operates and who has access to it. Between 2012 and 2015, 28% of referrals to CureTB for patients with verified or possible TB disease came from law enforcement agencies, including ICE, and 88% of those referrals were for an alien scheduled to be repatriated to Mexico (Figueroa et al., 2020). In 2017, 3.1% (287 out of 9,253) of patients with TB in the United States were in ICE detention at the time of diagnosis (Figueroa et al., 2020). Among patients with verified TB disease who were referred to other countries by CureTB, 78% completed treatment (Figueroa et al., 2020). These results show that with appropriate procedures and good implementation, transition of care can be accomplished.

### Program 2: Arizona's TB and HIV Meet and Greet Programs

Arizona has launched a nascent HIV care transition program for detained aliens repatriated to Mexico modeled on the state's TB "Meet and Greet" program. The TB program, which is described in more detail herein, includes all the components identified in the selected policy option from the analysis conducted in this chapter. Specifically, there is a data-sharing platform between ICE, and U.S. and Mexican health authorities at the state level (Arizona and Sonora). Repatriated aliens are physically met at the border upon removal in order to facilitate linkage to TB care and treatment; and detainees and ICE clinicians are educated by representatives from the Arizona Department of Health Services (ADHS) prior to repatriation.

ADHS and public health officials in Sonora, Mexico, have conducted this collaborative "Meet and Greet" program since 2002 (Lewis, 2006). The objective of the "Meet and Greet" program is to provide medical case management to encourage repatriated aliens to continue and

complete TB treatment despite repatriation to Mexico. The program is designed to address the problems created when people with active pulmonary TB are repatriated before their TB treatment is completed.

The TB "Meet and Greet" program involves the coordination of binational public health authorities and U.S. law enforcement staff. ICE detention facilities notify the local health department in Arizona of an impending removal of a detained alien being treated for TB. The local health department then contacts ADHS who notifies the TB program in the state of Sonora in Mexico (note: Arizona borders Sonora). The goal is to set a date and time for the repatriation (i.e., properly time the removal of the alien) so that there is the presence of Sonoran public health officials at the designated port-of-entry to meet the alien and facilitate linkage to continued treatment. Before repatriation takes place, an educator from ADHS will meet with the detained alien in ICE detention to educate them on TB, the importance of completing treatment, and how they will be linked to care upon removal to Mexico. Over the last few years, Arizona has begun an identical program for HIV called the HIV "Meet and Greet." There is no information available (yet) on the HIV "Meet and Greet" program in the published literature. Its existence was raised in the key informant interviews.

Arizona uses a medical electronic disease surveillance intelligence system (MEDSIS) (Arizona Department of Health Services, 2020). It is a statewide, secure (HIPAA compliant), web-based, centralized, person-based disease surveillance system hosted and supported by ADHS for use by providers and institutions responsible for reporting communicable diseases and for local health departments to conduct disease surveillance. It is updated in real-time; information entered into MEDSIS is immediately accessible by the local health department. Only approved MEDSIS users have access to data submitted by a provider. To facilitate the TB and

HIV "Meet and Greet" program, representatives from the Sonoran Department of Health have access to MEDSIS as do CureTB representatives and correctional facilities in Arizona, including ICE detention facilities. For TB and HIV care transition, the U.S. and Mexican authorities communicate using the alien's MEDSIS number and not their name.

### Limitations

In this policy analysis, the researcher solely conducted the rankings. The rankings do not include direct input from people who can provide and/or interpret information about the policies (i.e., subject matter experts, economists), people affected by the policy (e.g., ICE clinicians, HIV-infected Mexican aliens detained by ICE, U.S. and Mexican health authorities), nor people who administer resources related to the policy (e.g., public officials). In Bardach's eightfold path (Bardach & Patashnik, 2015), he makes the point that the extent to which evidence is assembled to evaluate each policy option involves a balancing of the "costs" needed to obtain the evidence versus the extent to which the new evidence would lead to better policy options. Because the rankings incorporate qualitative methodology (input from the key informant interviews) and information available in the published literature, it is not clear that new evidence provided by the groups listed above would necessarily lead to better rankings. Because the rankings are subjective, the rationale for each is documented in this chapter.

A limitation to this policy analysis is that several identified barriers in the care transition of HIV-infected aliens repatriated to Mexico were not explicitly addressed in one of the policy options. These barriers, identified in the literature review (Chapter 2), relate to challenges faced by the HIV-infected aliens once they are repatriated to Mexico. They include stigma and mistrust of Mexican state and local government (due to state and local politicians expressing hostility regarding immigrant access to services), which impact willingness to use government health

services (e.g., a CAPASIT), and transportation challenges to reaching a CAPASIT for regular care (they are not yet ubiquitous all over Mexico). Because this research focused on how to improve the actual point of HIV care transition between the United States and Mexico and less on the barriers to continued care on the Mexican side, these identified challenges have been noted and have been suggested in Chapter 4 (Results and Discussion) as areas for future research.

### **CHAPTER 6: PLAN FOR CHANGE**

The policy analysis in Chapter 5 identified two policy options to improve HIV care transition. The strongest option for improving HIV care transition is the development of a U.S.-Mexico HIV/AIDS continuity of care program that would include a platform for the sharing of HIV data and medical records. The CureTB program and Arizona's TB and HIV "Meet and Greet" program described in Chapter 5 could serve as useful models for a national program. In addition, expanding the CureTB program to include HIV could be a possibility to address the long-term policy option. A short-term step toward this longer-term policy goal is to ensure implementation of extant ICE standards for HIV care transition, which include the provision of a 30-day supply of HIV/AIDS medication, referrals to community-based providers, and a medical care summary. This short-term policy option plays a critical role in ensuring HIV care transition and could be a viable option politically since it is already an ICE detention standard, so it does not involve creating any new program or allocating additional funding.

If implemented, these policy solutions should improve HIV care transition for detained aliens removed by ICE to Mexico. In fact, the U.S.-Mexico HIV/AIDS continuity of care program should include the collection of outcome data to measure whether the program is successful in linking repatriated HIV-infected aliens to continued care in Mexico (and therefore not causing treatment interruption). But how can the policy solution(s) grounded in the results of the mixed-methods research be packaged and transformed into meaningful policy change? Using

Kingdon's (1984, 1995) MSF as a model, this chapter will describe an approach to pursue these policy options.

# The Policy Stream: ICE's HIV Care Transition Detention Standard

In regard to pursuing the short-term policy option, ICE should already have the funding allocated for implementation of its detention standards (2011 PBNDS and the 2019 NDS) via Congressional appropriation to DHS. This means that the policy action needed relates to the implementation of ICE's HIV care transition detention standards—in other words, an operational policy change. After consultation with various stakeholders, including dissertation committee members, it was decided that the best approach would be to pursue this policy option at the program level—by engaging with the leadership of IHSC who oversee the medical care detention standards. The goal of the engagement would be to learn about the barriers ICE is facing regarding implementing the HIV care transition standard as well as the levers that need to be "pulled" for ICE to begin to implement the care transition standard and coordinate with the health authorities ahead of repatriation. Since ICE is reportedly implementing these standards in Arizona—through ICE's participation in Arizona's HIV "Meet and Greet" program—it could be the levers are more straightforward to "pull." In particular, the case might be easier made when sharing the estimated number of HIV-infected aliens ICE repatriates each year to Mexico from across all ICE facilities in the United States (based on FY 2018 secondary data): 75 aliens. While this is most likely an underestimate of the true number of HIV-infected aliens ICE repatriates to Mexico, it does give an indication of the current volume ICE is handling for which it would need to ensure care transition.

An ideal forum to consider approaching IHSC leadership is via the U.S.-Mexico Border TeleECHO program (Border ECHO [Extension for Community Health care Outcomes]). The

goal of Border ECHO is to virtually connect key stakeholders along the U.S.-Mexico border working with migrant communities, including asylum seekers and recent migrants. Each of the closed sessions focuses on a topic that participants have requested. Sample topics include "Improving Communication with Customs and Border Patrol, Immigration and Customs Enforcement." In addition to a more formal presentation, in each session, time is scheduled for problem-solving and brainstorming for any U.S.-Mexico border health problems or challenges that need immediate feedback and advising from the network of participants. Managed out of the University of New Mexico Health Sciences Center, the Border ECHO program includes participation from U.S. and Mexican health authorities at the local, state, and federal level.

Because Border ECHO has convening power and, in the past, has worked to address topics related to ICE, the investigator will send a request to Border ECHO to consider convening a session to consider this policy topic. The information on how to contact the management team of Border ECHO is publicly available on the University of New Mexico's website. To help inform the members of Project ECHO, the investigator intends to develop an executive summary of the results of this research and summarize this shorter-term operational policy recommendation. The hope is that the Project ECHO community will be able to use this summary and the subsequent presentation to provide input and next steps for engaging with IHSC regarding the implementation of the ICE detention standard for HIV care transition.

### The Policy Stream: U.S.-Mexico HIV Continuity of Care Program

In regard to pursuing the long-term policy option of creating a national HIV care transition program, this policy proposal should not need legislation nor legislative oversight to be implemented. Rather, it can be a collaborative effort between key stakeholders: DHS/ICE and local, state, and federal health authorities in the United States and Mexico. Transnational data

sharing policies and platforms are not straightforward to implement, but instructive models are available, including CureTB and Arizona's MEDSIS. In addition, one possibility to address this long-term policy option is to consider the inclusion of HIV/AIDS care transition into the CureTB program. In the early 2000s, the San Diego County Health Department oversaw a program under CureTB called CureTB Plus, and it focused on HIV/AIDS care transition (Ocaña M, personal communication, February 25, 2020).

Similar to the shorter-term policy solution, the investigator intends to develop an executive summary of the results of this research and this long-term policy recommendation. The primary audience for the executive summary will be the Border ECHO Program. If requested by the Border ECHO program, a framework can be developed to outline the key components to be included in such a program. Border ECHO is a good convener to explore creating this program both because the architects of Arizona's "Meet and Greet" programs are members and also because of the relationship that members of Border ECHO have to CureTB and other binational programs already working on HIV care transition. If this longer-term strategy can find a "window of opportunity" within the Executive Branch, then funding would most likely be able to be reprogrammed to support creating the program and the data/medical record exchange platform. This policy proposal does not need legislation nor legislative oversight to be implemented. Rather, it can be a collaborative effort between key stakeholders: DHS/ICE and local, state, and federal health authorities in the United States and Mexico.

Another avenue to explore in considering this longer-term solution relates to HHS advisory committees. As mentioned in Chapter 1, a straightforward, formal process took place to create the now-formal policies for TB care transition in repatriated aliens. The investigator recommends a similar process be considered for HIV care transition in repatriated aliens. As a

reminder, in 2002, the CDC ACET recommended that a working group be formed to review problems with post-detention TB treatment of aliens. ACET recommended that removal should only occur after verifying that necessary treatment is available at the destination (Nolan et al., 2003). In 2004, ICE implemented a policy allowing for a temporary "medical hold" so that the IHSC could arrange for continuity of care before removal (Fenton & Castro, 2006). In 2005, ICE formalized policies for referring medical cases to two organizations: CureTB (San Diego County Health Department, San Diego, CA) or TB Net (Migrant Clinicians Network, Austin, TX) (Schneider & Lobato, 2007).

The longer-term solution of creating an HIV care transition program could be well-placed to be considered by another of CDC's federal advisory committees—the Board of Scientific Counselors (BSC) which advises the CDC Deputy Director for Infectious Diseases (DDID) as well as the HHS Secretary concerning strategies, goals, and priorities for the programs and research within the three infectious disease national centers at CDC. The board consists of 17 members as well as a liaison from the Public Health Agency of Canada and the Secretariat of Health of Mexico. Similar to the approach that ACET took to address TB care transition in migrants, including repatriated aliens, it could be that thought should be given to approaching the BSC, DDID.

The challenge for this long-term policy option is its timing. As highlighted in Chapter 5, this policy option does not currently benefit from a window of opportunity that this researcher can see (as of Spring 2020). While an issue that the Mexican Secretariat of Health has raised in the recent past, the magnitude of the issue for HIV care transition is not fully clear. Data are not available on the prevalence of HIV/AIDS in aliens repatriated by ICE to Mexico. Few aliens in ICE detention are known by ICE to have HIV/AIDS (a topic to be potentially be explored

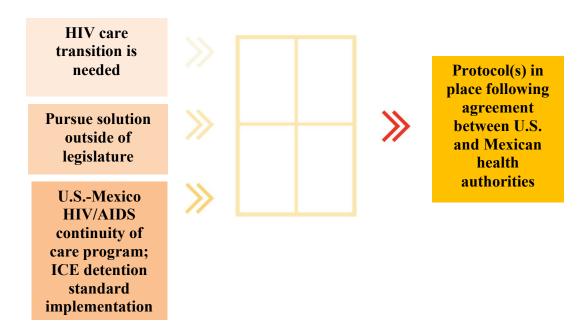
further, but it is outside the scope of this dissertation). HIV/AIDS does not rise to the same level of concern for ICE staff, as say, TB. Based on the investigator's calculations using FY 2018 secondary data (see Chapter 4), only an estimated 63 aliens are diagnosed with HIV/AIDS each year in ICE detention. Therefore, the recommendation for this policy option is to keep it as longer-term. Inform Border ECHO, write the executive summary, and wait for a "window of opportunity" to open.

Because of the lack of a clear "window of opportunity" in Spring 2020, this chapter further explores an alternate policy option that could help with meeting the goals being sought—to exchange HIV/AIDS data and medical records between the United States and Mexico. This policy option does have a "window of opportunity" in Spring 2020.

# Implementing the Policy Solution(s) Using Kingdon's MSF

Figure 6 visually outlines the main question this exploratory research aimed to address: the political milieu as it relates to the problem and the proposed policy solution(s) described earlier. According to Kingdon, these three streams need to come together at the right time ("a window of convergence" or "window of opportunity") to implement a policy solution.

Figure 6. Applying Kingdon's (1995) MSF to Create HIV Data and Medical Sharing Protocols between the United States and Mexico



# The Political Stream: Actualizing the Policy Recommendation(s)

Broadly speaking, Kingdon's "political stream" refers to the milieu of community, governmental leaders, advocates, and stakeholders who have a voice in determining how the agenda is set for a given problem and the approach to address it. As noted earlier, new legislation is not essential. Moreover, the cooperation of the Executive Branch will greatly improve the likelihood of success because negotiating out the long-term proposal for a binational HIV continuity of care program (with a data exchange platform) will take cooperation of the Executive Branch. Given the strong interest in a solution beginning at the lowest point (program leads), already working with key stakeholders is a solution. The goal is a bilateral agreement with much detail. It will require buy-in from ICE.

### **Optimal Window of Opportunity – An Area for Further Research**

In following Kingdon's (1984, 1995) MSF and in light of the discussion above about the need for a clear "window of opportunity" in Spring 2020 to move forward the longer-term policy

solution—it does seem that to gain executive branch (and if needed, legislative branch) support for a binational data/medical record exchange platform it needs to be larger than singularly focused on HIV.

The Spring 2020 pandemic of SARS-CoV-2 could present two "windows of opportunity" to address the short- and long-term policy options. First, when the coronavirus situation is eventually over, there will be after action reviews and other analyses of how ICE managed the outbreak. These may prompt reconsideration of the overall public health standards for how ICE deals with detainees. So, this might present a window of opportunity for DHS to also look at HIV care transition guidelines and practices. Second, the pandemic may lead the Executive Branch to pursue a U.S.-Mexico, or even a U.S.-Mexico-Canada (i.e., North American) surveillance/medical record exchange platform to be able to determine a defined list of diseases of public health importance—and ensure HIV is on that list. To fully explore the SARS-CoV-2 "windows of opportunity" and related policy options is beyond the scope of this research paper.

As the Coronavirus pandemic is reminding everyone, in today's globalized world, infectious disease threats have become transnational in nature and, therefore, require effective cross-border approaches to detect and respond to them. Given the length of the U.S.-Mexico border and its vulnerability to the introduction and rapid spread of potential threats to public health, it would be valuable to consider a policy option for all infectious diseases—perhaps modeled on Arizona's MEDSIS platform discussed in Chapter 5. MEDSIS is a secure (HIPAA compliant), web-based, centralized, person-based disease surveillance system hosted and supported by ADHS for use by providers and institutions responsible for reporting communicable diseases and for local health departments to conduct disease surveillance. It is updated in real-time, and information entered into MEDSIS is immediately accessible by the

local health department. Only approved MEDSIS users have access to data submitted by a provider. This platform might be a helpful model for a larger, national platform because the MEDSIS model can support TB and HIV care transition for repatriated aliens while simultaneously serving as the surveillance system for the state.

Pursuing a North American surveillance platform would be in line with over a decade of global efforts to develop new approaches to emerging and re-emerging infectious diseases—part of the growing recognition that disease events, whether natural, accidental, or intention, threaten not just public health, but national, regional, and global security interests (Crouse Quinn & Kumar, 2014). The two major platforms for country action emerging out of these global efforts are the Global Health Security Agenda and the revised 2005 International Health Regulations (IHR) (Kimball et al., 2008). Both platforms highlight the need for functional cross-border public health surveillance networks. The IHR (Article 21 on ground crossings, Article 44 on collaboration and assistance, and Article 57 on other international facilitating agreements) encourages neighboring countries to cooperate directly in disease surveillance sharing and coordinating responses to public health problems affecting more than one country (Heymann et al., 2015).

# Limitations of the MSF Model

For the purposes of this research study, Kingdon's (1984, 1995) MSF has three limitations: 1) it is a model that is most helpful to the legislative process and applies less to recommendations made of federal agencies; 2) it deals with policymaking under conditions of ambiguity when there are many ways to think about the problem whereas the results of this research showed that communication is the underlying issue; and 3) it requires that attention be paid to the issue by advocates/stakeholders to a degree higher than what might be needed to

encourage ICE to implement its detention standards or to encourage U.S. and Mexican authorities to work on creating a clinical data and medical record sharing platform. The development of protocols and processes can be done by motivated government employees without legislation from Congress.

#### Conclusion

This research supports U.S. and Mexican authorities to identify best practices, challenges, and opportunities for improved HIV care transition in the population of aliens detained by ICE and repatriated to Mexico. The exploratory research also provides insight into the current status of HIV care transition in this population and expectations for a well-functioning HIV care transition process. If implemented, the short- and long-term policy options will improve the communications, coordination, and binational collaboration for HIV and AIDS care transition. Further exploration of actions needed for ICE to strengthen the management of HIV-infected aliens in detention facilities, both with respect to enhancing testing of detained migrants and increasing implementation of ICE HIV care transition standards, would be fruitful. Avenues for further research that would help support advocacy and policy development to improve HIV care transition for repatriated aliens include carrying out studies to better define the prevalence of HIV/AIDS among detained aliens and determine the outcomes of HIV care transition for aliens.

Given the seriousness of HIV infection, the clinical implications of interrupted antiviral therapy for individuals, and the availability of free HIV treatment in Mexico for all Mexicans, care transition for HIV-infected aliens detained by ICE who are repatriated to Mexico is particularly important. Continuing the status quo means not having HIV care transition occur in a systematic way, except in isolated cases that are exceptions. Even modest changes in how the

HIV care transition process happens in the population of detained, HIV-infected Mexican aliens will have an important public health impact. Perhaps one of the key informants put it best:

The scenario is that this person's going to be deported from the United States anyway, and the best that we can do is to make sure that they receive care in Mexico, that those physicians have the best clinical information to make their decisions on how to go forward in treating that person.

### Disclaimer

While completing this doctoral degree, the investigator was employed by CDC. This dissertation was not linked to the work required in this role. The analysis, results, and conclusions are the investigator's work conducted as a student and do not in any way represent CDC or the investigator's work at CDC.

# APPENDIX A. STUDIES INCLUDED IN THE LITERATURE REVIEW

Article PMID	Author (Year)	Туре	City/ Country(ies)	Focus	Major findings
Website	Aids Education and Training Center. (2016)	Fact sheet	Central America, Mexico	Improving continuity of care for migrant patients with HIV	N/A
22653772	Dara et al. (2012)	Consensus Statement	WHO European Region	The development of a minimum package of interventions to improve cross-border TB control and care	A legal framework for TB cross-border collaboration is essential.
28633696	Dara et al. (2017)	Case studies	Australia, Italy, Norway, The Netherlands, United Kingdom, United States	Policies and practices for cross-border collaboration for TB continuity of care in low-incidence countries	Transnational data sharing is key and must be conducted in- line with privacy protection rules
29176097	Martinez- Donate et al. (2017)	Research, cross- sectional survey	Tijuana, Mexico	Access to health services among Mexican migrants to the United States across migration phases (e.g., pre-departure, return)	Returnees had lower likelihood of receiving health care and higher rates of forgone care than their counterparts at pre-departure
29997050	Page et al. (2018)	Policy	Global with emphasis on Americas Region, Mexico	Implications of enhanced immigration enforcement on the health and well-being of HIV-infected migrants	A systems approach is needed to address transnational HIV care
22562390	Rangel et al. (2012)	Research, cross- sectional survey	Tijuana, Mexico	Estimating HIV risk behaviors among U.S. deportees to Mexico	Estimates rates of HIV for deported males were higher than the national rate in Mexico.

17572305	Schneider & Lobato (2007)	Research, epidemiolog y	United States	Review TB case counts, frequency distributions, duration of treatment and custody for ICE detainees during 2004-2005	Patients are usually deported before completing TB therapy. Because of removal, and sometimes reentry into the U.S., unique collaborations are required to support completion of treatment.
DOI: 10.1016/ j.polsoc.2014 .03.003	Truby (2014)	Policy	Mexico	Analyzing how HIV- focused civil society organizations operate at Mexico's northern and southern borders	At the U.SMexico border, U.S. security interests are the primary financiers for HIV-focused civil society organizations
26886720	Tschampl et al. (2016)	Research, epidemiologi c	Global	The proportion of patients referred to transnational care-continuity and mgmt. services during relocation	Scale-up of transnational TB services for persons leaving the U.S. and at high risk for treatment interruption is possible
20845844	Venters et al. (2009)	Policy	United States	Examine reports on detainee health issues and conduct analysis of the ICE health plan used to govern HIV specialty care	The system of immigration detention in the U.S. fails to adequately screen detainees for HIV and delivers a substandard level of medical care to those with HIV
29657545	Wassink (2018)	Research	Mexico	Mexican return migrants' health insurance coverage and access to medical care	High rate of un- insurance and limited access to medical care among the growing population of Mexican return migrants

### APPENDIX B. KEY INFORMANT INTERVIEW GUIDE

Good afternoon, [insert name]. Thank you for agreeing to participate in this study which is a component of my doctoral dissertation for the University of North Carolina, Chapel Hill. This interview should take 30-40 minutes and will consist of 13 questions.

I am implementing an exploratory research study looking at ways to improve HIV care transition for HIV-infected aliens detained by U.S. Immigration and Customs Enforcement and removed to Mexico. I am also exploring whether there are lessons that can be learned from tuberculosis care transition in this same population. The purpose of the key informant interviews is to enhance my understanding of some of the perceptions about HIV care transition in this population and the factors that are facilitating or hindering its success. The results of this study will be used to inform policy recommendations that may be helpful to address this issue.

The information collected in this interview will be kept completely confidential. Your name will not be connected to your answers in any way. Your name will not be used in any study report, final report, or publications. Once the data have been compiled, all identifying information associated with your answers will be removed.

Your participation in this study is purely voluntary, and there are no consequences if you refuse to participate. At any time during our conversation, please feel free to let me know if you have any questions or if you would rather not answer a specific question. You can also stop the interview at any time for any reason.

With your permission, I would like to record our interview. This will ensure that none of your important insights are missed. The audiotape will not have any names on it (only an identifier code) and will be kept in a secure location. Tapes and transcriptions will be destroyed at the end of the study. The interview will not be recorded if you prefer. If you prefer it not to be, I will take detailed notes.

- Before we begin, do you have any questions about the study or the interview?
- May we record the interview?

## [Turn on recording equipment.]

Before we begin, I will review a few terms that will be used in the questions. In order to ensure consistency, all terminology used will be consistent with that of the U.S. federal government.

- *Alien* refers to any person who is not a citizen or national of the United States.
- For this specific research project, HIV and tuberculosis care transition refer to the coordination and continuity of health care for HIV- and/or active TB-infected aliens removed from immigration detention in the United States to Mexico.
- Removal occurs when the federal government orders that an alien be expulsed from the
  United States. This expulsion may be based on grounds of inadmissibility to the United
  States, such as aliens seeking asylum, or deportability for a violation of immigration law.
  - Do you have any questions about the definitions before we move on?

# Introduction

- 1. To start off with, I am going to ask a little bit about you. What is your current position?
- 2. Can you tell me about your work history engaging with immigration detention and/or with detained aliens after their removal from the United States?

Perceptions of the current quality of HIV care transition for detained HIV-infected aliens removed to Mexico and challenges affecting the care transition.

- 3. How would you describe the current situation regarding the access detained HIV-infected aliens have to continued HIV care and treatment in Mexico upon arrival?
- 4. How would you characterize the coordination of HIV care transition between U.S. and Mexican authorities? How could this cooperation be improved?
- 5. What are the most important administrative barriers for HIV-infected aliens to access HIV care and treatment in Mexico?
- 6. What are the main challenges for continuity of HIV care and treatment in this population?
- 7. What would an ideal HIV care transition process look like to you?

Lessons from tuberculosis care transition for removed aliens that can be applied to HIV care transition

- 8. How would you describe the current situation regarding tuberculosis care transition for detained aliens removed to Mexico?
- 9. What would an ideal TB care transition process look like to you?
- 10. In addition to tuberculosis, are you aware of models of care transition in other settings that might provide insights on how to improve HIV care transition in this population? [If the respondent asks for an example, options could include persons transitioning from prison to the community, military to civilian life, or adolescent to adult care.]

# Wrap up and Closing

- 11. Is there anything else that you would like to add about any of the topics that we've discussed or other areas that we didn't discuss but you think are important?
- 12. What is the most important message that you want me to take away from this interview?
- 13. Do you have any questions for me at this time?

Thank you for taking the time to answer these questions. Your participation in this interview greatly contributes to the research project and to increasing our understanding around HIV care transition for detained aliens removed to Mexico. Your answers will be compiled with the answers of all other interviewees. Please feel free to contact me at any time if you have any questions about this interview or the research project.

### Addendum to Interview Guide: List of Possible Probes

- Can you tell me more? (asking for more information)
- Can you provide more details? (asking for more information)
- Can you give me another example? (asking for more information)
- Could you explain your response more? (asking for an explanation)

### APPENDIX C. INTERVIEW CONSENT FORM

University of North Carolina at Chapel Hill Consent to Participate in a Research Study – Adult Participants

**IRB Study #:** 18-2739

Title of Study: How can HIV care transition be improved when U.S. Immigration and Customs

Enforcement repatriates detained aliens to Mexico?

### **CONCISE SUMMARY**

The purpose of this research study is to look at ways to improve HIV care transition for HIV-infected aliens detained by U.S. Immigration and Customs Enforcement and removed to Mexico. The purpose of the key informant interviews is to enhance understanding of some of the perceptions about HIV care transition in this populations and factors that are facilitating or hindering its success. The results of this study will be used to inform policy recommendations that may be helpful to address this issue.

Participants in the telephone interviews will be asked for no more than 60 minutes of their time. Each interview should take about 40 minutes.

The greatest risk of this study is the possibility of loss of confidentiality.

If you are interested in learning more about this study, please continue to read below.

### What are some general things you should know about research studies?

You are being asked to take part in a research study. To join the study is voluntary. You may choose not to participate, or you may withdraw your consent to be in the study, for any reason, without penalty.

Research studies are designed to obtain new knowledge. This new information may help people in the future. You may not receive any direct benefit from being in the research study. There also may be risks to being in research studies.

Details about this study are discussed below. It is important that you understand this information so that you can make an informed choice about being in this research study.

You will be given a copy of this consent form. You should ask the researchers named above, or staff members who may assist them, any questions you have about this study at any time.

### What is the purpose of this study?

The purpose of this exploratory research study is to look at ways to improve HIV care transition for HIV-infected aliens detained by U.S. Immigration and Customs Enforcement and removed to Mexico. The study is also exploring whether there are lessons that can be learned from tuberculosis care transition in this same population. The purpose of the key informant interviews is to enhance understanding of some of the perceptions about HIV care transition in this

population and the factors that are facilitating or hindering its success. The results of this study will be used to inform policy recommendations that may be helpful to address this issue.

You are being asked to be in the study because of your level of experience with immigration detention in the United States and/or with HIV and/or tuberculosis care transition for detained aliens removed to Mexico by U.S. Immigration and Customs Enforcement.

## Are there any reasons you should not be in this study?

You should not be in this study if you are not familiar with immigration detention in the United States and/or with HIV and/or tuberculosis care transition for detained aliens removed to Mexico by U.S. Immigration and Customs Enforcement.

### How many people will take part in this study?

There will be approximately nine (9) people in this research study.

# How long will your part in this study last?

Your telephone interview should take no longer than 40 minutes to complete; however, you are asked to allot 45 to 60 minutes for the interview so that you have the opportunity to elaborate when responding to questions.

### What will happen if you take part in the study?

If you decide to participate in an interview, the Principal Investigator will work with you to schedule the interview and will ask you to block one hour. The interview will be conducted by telephone by the Principal Investigator.

At the beginning of the telephone interview, the Principal Investigator will open by sharing the purpose of the interview and the details of the study. The Principal Investigator will ask you for your verbal consent to be interviewed. Should you provide your verbal consent to be interviewed, the Principal Investigator will then ask for your consent for the telephone interview to be recorded. The interview will not be recorded if you prefer. If you prefer it not to be, the Principal Investigator will take detailed notes.

The Principal Investigator will then inform you that your name will not be connected to your answers in any way. Your name will not be used in any study report, final report, or publications. Once the data have been compiled, all identifying information associated with your answers will be removed.

At any time during the interview, you can let the Principal Investigator know if have any questions or if you would rather not answer a specific question. You can also stop the interview at any time for any reason.

The Principal Investigator will ask you if you have any questions about the study or the interview. The Principal Investigator will then review several terms with you that will be used in the questions that will comprise the interview. The interview will consist of fifteen questions.

# What are the possible benefits from being in this study?

Research is designed to benefit society by gaining new knowledge. You will not benefit personally from being in this research study.

# What are the possible risks or discomforts involved from being in this study?

The greatest risk of this study is the potential for loss of confidentiality. Study staff and the Principal Investigator will use their best efforts to protect your information and keep it confidential, however there is always a risk of disclosure.

# How will information about you be protected?

Your name will not be connected to your answers in any way. You will be issued an ID number that will be used for your interview, rather than your name. Your name will not be used in any study report, final report, or publications. Once the data have been compiled, all identifying information associated with your answers will be removed.

Audio recordings of the key informant interviews will be transcribed; names and other identifiers will not be included in the transcribed copies. Electronic copies of transcriptions will be stored on password-protected computers on a secure server. Keys linking names and personally identifiable information with ID numbers will be destroyed once the database is complete and ready for analysis. All data will be on password-protected servers until the study results are completed. All field notes will be kept in a locked cabinet in the Principal Investigator's office. Access to print and electronic files will be restricted to the study investigators. When the study results are completed, the electronic and paper data will be destroyed.

Although every effort will be made to keep research records private, there may be times when federal or state law requires the disclosure of such records, including personal information. This is very unlikely, but if disclosure is ever required, UNC-Chapel Hill will take steps allowable by law to protect the privacy of personal information. In some cases, your information in this research study could be reviewed by representatives of the University.

At the beginning of the interview, the Principal Investigator will ask you for your consent for the telephone interview to be recorded. The interview will not be recorded if you prefer. If you prefer it not to be, the Principal Investigator will take detailed notes. At any point during the interview you can request that the audio recording be turned off.

### What if you want to stop before your part in the study is complete?

You can withdraw from this study at any time, without penalty. You can request that the interview be stopped at any point. After the interview, you can request that your interview responses not be used in the study.

### Will you receive anything for being in this study?

You will not receive anything for taking part in this study.

### Will it cost you anything to be in this study?

It will not cost you anything to be in this study.

# What if you have questions about this study?

You have the right to ask, and have answered, any questions you may have about this research. If you have questions about the study, complaints, or concerns, you should contact the researchers listed on the first page of this form.

# What if you have questions about your rights as a research participant?

All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have questions or concerns about your rights as a research subject, or if you would like to obtain information or offer input, you may contact the Institutional Review Board at 919-966-3113 or by email to IRB subjects@unc.edu.

# **Participant's Agreement**:

I have read the information provided above. I have asked all the questions I have at this time. I voluntarily agree to participate in this research study.

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