

# Screening Out

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# Introduction

“Not all suffering is illness; some suffering is political.”

– BAIJAYANTA MUKHOPADHYAY, *A LABOUR OF LIBERATION*

Canadians would march in the streets if their federal immigration system excluded applicants on the basis of the colour of their skin, as it once did.<sup>1</sup> Yet neither people like the late great physicist Stephen Hawking, who was physically disabled, nor people like the basketball giant Magic Johnson, who lives with HIV, would currently be able to settle in Canada. As it stands, prejudice on the basis of a person’s health and development status is written into Canadian immigration law.<sup>2</sup> Remarkably, Canadians know woefully little about this topic. With this book, I aim to redress this lack of awareness.

I have studied this topic very closely since 2008. Given that both the creation of laws and the fulfillment of their intentions occur through human practice, this health-based prejudice could be made to vanish. And, as it happens, I have a strong personal commitment to countering this specific form of legal inequity: I live with an illness that would probably exclude me from permanent residency if I had not been born, by total and utter randomness, in Canada. The unfairness of this situation profoundly bothers me, as I have communicated to academic and

nonacademic audiences through a film, a case study, a scholarly blog, a vodcast, and poetry – a published example of which opens this book.<sup>3</sup> The need to confront the inequity of the Canadian immigration system deeply motivates me, and the analysis between these covers can inform legal reform work.

*Screening Out* is an institutional ethnography of the Canadian immigration system from the perspective of people who are HIV-positive. In the first months of 2002, a policy change by Canada's federal department responsible for immigration made mandatory HIV testing part of the immigration medical examination.<sup>4</sup> This was the first change in fifty years. Anyone who has filed an application for Canadian permanent residency will be able to share that being medically examined by a specifically designated general practitioner is necessary. That is true whether a person applies from inside or outside of Canada, although the vast majority of the estimated 925,000 annual immigration medical examinations happen outside of the country.<sup>5</sup> However, only those who have been tagged "abnormal" (to use the state's term) because of their bodily status can tell us what this institutional tattoo looks and feels like, and what it triggers in their lives, as they continue what instantly becomes a complicated application process riddled with built-in snares.<sup>6</sup> People who have been institutionally tagged and tattooed with an HIV-positive diagnosis populate the pages of this book.

As part of a sprawling and opaque bureaucratic system, the Canadian immigration application is a text-mediated process shaped by legal concepts that originate in the *Immigration and Refugee Protection Act* and the *Immigration and Refugee Protection Regulations*.<sup>7</sup> These concepts shape the immigration practices of HIV-positive applicants, the immigration doctors and radiologists contracted by the Canadian state, and behind-the-scenes medical officers and visa and immigration officers contracted or employed by the immigration department inside and outside of Canada. Within an applicant's process, a critical moment is when one gets the result of an HIV test, which, if positive, catalyzes the collection of medical data about the person, data that are factored into decisions about the person's admissibility or inadmissibility for Canadian permanent residency. The textual basis for this decision making is an official

medical report produced by an immigration doctor based on clinical-diagnostic laboratory results. This medical report advances through the bureaucracy, passing through the many hands of people working for or on behalf of the Canadian state across the world, and all of these sites are connected by the work that people do and how they do it as they produce, use, and share myriad types of “texts.” These texts include, but are not limited to, print, film, photography, television, mass and electronic media, and radio. The texts used in this analysis include legislation, policies, regulations, handbooks, instructions, directives, public education material, research reports, websites, medical files, people’s individual immigration paperwork, and my correspondence with interlocutors. Further along in this Introduction, I define and discuss how I have used texts analytically in this book, and how I am asking the reader to relate to them.

The empirically based argument I develop in this book is that the Canadian state’s ideological work with regard to HIV policy and mandatory screening involves a set of institutional practices that are highly problematic for immigrants living with HIV. I take as my object of analysis the Canadian immigration system and, throughout this book, seek answers to several questions: How is this vast institutional complex organized? What is involved organizationally? How are the contexts governed? How is the mandatory HIV testing of immigrants organized? What are the consequences of this organization for applicants living with HIV? The analyses offered are supported by multilingual institutional ethnographic fieldwork that I carried out in Quebec and Ontario during my doctoral training at the University of Ottawa, which culminated in a study that brought “light and order to the chaos and opacity of the Canadian institutional landscape of public health and immigration and the entanglements associated with these.”<sup>8</sup> *Screening Out* has absolutely nothing to do with policy analysis governed by positivism’s obsession with number crunching and quantitative measuring. Rather, the analysis stems from an entirely people-centred research process. It is unapologetically a human-centred study that reprises and updates earlier data. It responds to calls for sociologists, and qualitative health sociologists more specifically, to systematically document and make explicit the

institutional origins and functioning of human suffering, as anthropologists have.<sup>9</sup> It joins with academic research and activism that have problematized the confluence of medical and legal reasoning in the Canadian immigration system, past and present.<sup>10</sup> Finally, this analysis responds to calls to subvert “policy relevant” approaches that dominate in studies of migration and mobility by intentionally displacing state-centric accounts of how immigration systems work and how they impact people’s personal and professional lives.<sup>11</sup>

The analysis on which *Screening Out* is built allows me to stand on firm ground in making two claims about what needs to change so that Canadians cease their unwitting support for institutionally initiated problems happening within their immigration system. These problems are happening through the immigration medical program, and they directly affect the lives of applicants, doctors, lawyers, and state functionaries whose labour is derived from and coordinated by the system.



Since 2008, during which time I have written, spoken, and taught about the Canadian immigration system and about the inner workings of the medico-administrative practices that regulate it and people living with HIV, my materials have been received, time and again, with great interest and enthusiasm: people know precious little about how this system works with any detail or certainty, and they are keen to learn. Generally speaking, Canadian-born citizens know little about how the system *actually* works, and in this group, I include people whose parents or kin were born outside of Canada. Student and scholarly audiences alike are fuzzy about the immigration application process and about the health and work experiences of foreign-born residents and citizens. They know even less about medical-screening rules and related procedures, whether historical or current.

My first claim – that changes to decision-making practices regarding immigration medical inadmissibility are needed – is empirically justified. These changes have to be supported by what is *actually happening to applicants* and have to be based on how other people in their professional roles as doctors, lawyers, and state functionaries are *actually being asked to work* within the immigration medical program as it is

currently organized. The analysis and results discussed in this book provide a robust empirical basis for the evidence-informed and doable recommendations that I make in the Conclusion. A Canadian-born reader of a draft of this book, educated to the highest possible level in the Canadian education system, wrote,

I am astounded how ignorant I am of immigration policies etc., and the impact on people who have to wade through them, like the proverbial molasses in January or a bad dream when you cannot run away from danger because your feet are stuck in mud or cement and the whole thing is closing in on you ... Who can take these blows and still carry on?

This book is intended to be instructive to a public for the most part unfamiliar with the people, politics, places, problems, policies, practices, and procedures discussed between these covers. It is very important, particularly for people with no first-hand experience of immigrating to Canada, that clear understandings of the immigration system and its processing of applicants be developed *based on applicants' experiences* because “the system” and “its processing” and “its practices” bind applicants to us and us to them. Period. Pointedly, and based on over seven decades of experience in “Canadian society,” the same erudite reader critiqued herself and her compatriots – “we” – exclaiming, “[This is] dissemination of academic knowledge [through] compelling human stories that are lost under a superficial ‘we know all about immigrants!’ attitude, *and we don’t*” (emphasis added).

What I *do* know from personal experience in various milieus, classrooms, and conference rooms, for example, is that the Canadian public is largely unaware of any of the circumstances specifically related to medical screening. Unless an immigrant or refugee person tests positive for HIV, the person will not likely know that they were tested for HIV in the first place. Moreover, Canadian-born citizens know little about how the immigration system actually functions and are even less well informed about medical policies, practices, and procedures that take place within this context. Most people are not personally involved with immigration HIV testing, and the practices to which it gives rise are

taken for granted, or not evident to most, or both. What we see is that, because the HIV test is *mandatory*, its associated practices are enacted in immigration medical examinations all over the world, most of which take place outside of Canada. Involved are immigration doctors and the personnel who draw blood and interpret the diagnostic test results. Given that HIV testing is normatively framed as good practice by health providers and medical professionals, it is not easy to open up, problematize, and produce critical understandings of how things actually work. It is precisely because of this normative position – the view that testing is de facto a social and health good – that questioning the policy of mandatory testing as part of the state’s HIV-specific regime is challenging.

My second claim – that changes to HIV-specific practices are necessary – is empirically warranted. As with the first claim, changes must be empirically informed by what *actually* happens personally for permanent residency applicants and also professionally for those doing doctoring, lawyering, and bureaucratic work within the immigration medical program as it is currently organized. Within this book is the empirical basis for the evidence-informed and achievable suggestions that appear in the Conclusion.

In the end, I conclude that because legal histories of immigration have not sufficiently explored how the dominant institutions of medicine, public health, criminal justice, and immigration legally converge and interlock to oppress and make demands of applicants, these imbrications and their effects have been likewise underexplored in classrooms and thus poorly understood by Canadians.<sup>12</sup> This is a place where a vital and rapid role can be played by those of us whose professions and responsibilities include educating students of all ages across Canada. *Screening Out* affords Canadians – and prospective future Canadians – the opportunity to jump inside Canada’s immigration system to learn about how the medical and legal aspects of this otherwise measureless and misty bureaucracy function from the inside out and from the bottom up. The book’s title, which I intend to be both evocative and provocative, refers to what is done *to* immigrant and refugee people and to what all applicants must *do* across time and in places all over the world where medical examinations take place if they are to have the possibility or hope of settling in Canada.

### **Embodied Knowledge, Disembodied Knowledge**

I set out to learn about the workings of the medical, legal, and bureaucratic practices that shape immigration to Canada because of two inter-related concerns. In a first instance, as detailed in the Preface, I was troubled by apprehensions and contradictory experiences related to the immigration medical examinations that immigrant and refugee women living with HIV, such as Fortune, had told me about.

Women in Montreal described what was involved for them within the immigration system. They told me about the particular place of HIV within their immigration application process. They experienced chronic and long-term material strain as well as “ontological insecurity ... an acute sense of not knowing what comes next” regarding how their HIV status was being institutionally seen, handled, and “processed.”<sup>13</sup> They suspected that HIV triggered events and actions that their HIV-negative counterparts did not face. They felt social difference because of their diagnosis. I listened to what happened to them and paid attention to the steps that they needed to take as a result of an HIV-positive diagnosis. Within women’s accounts were descriptions of interactions with federal and provincial offices and with local community-level organizations that serve people living with HIV, women, new immigrants, and nonwhite publics.

I came to know numerous women very well. I cared about their well-being and that of the children they were supporting and from whom they were often separated for years at a time because of how international borders are set up and maintained. I wanted to understand how their troubles were responses to the way that public systems are produced in the first place. A significant part of my duties as a community services worker was to accompany women to medical appointments, meetings with lawyers, and sessions with faith leaders. I was invited to participate in social rituals unrelated to my day job. Baptisms of babies, birthday parties, church services, and community fundraisers brought joy. I was learning, as they were, how to move through federal and provincial bureaucracies of health, immigration, and social services. We collaborated in helping each other to see, think, and explore “organizationally” so that we could get what we needed from workers behind the many institutional windows and wickets where we had to queue up and wait.<sup>14</sup>

These situations meant that I found myself profoundly stirred – as a woman, a community services worker, and a person familiar with how a diagnosis with HIV shapes a life. In a second instance, therefore, the discrepancies between what I knew of women’s accounts of immigration HIV testing, on the one hand, and academic representations of these same experiences, on the other hand, disturbed me.

These concerns, which melted away all distinctions between the personal, professional, and scholarly dimensions of my existence, propelled me to design an inquiry into the state’s position regarding how HIV-related policy and practices were being implemented in its immigration medical program and, by extension, in the professional practices of its immigration doctors, radiologists, medical officers, and visa and immigration officers working inside and outside of Canada. I was curious to learn how the authoritative claim that all was well with the immigration HIV testing and medical examination was arrived at. At best, nuance was needed. At worst, a full-blown corrective was required. As the two claims above demonstrate, the latter proved necessary. Our collective corrective action on these issues is yet to come.



As I sit writing *Screening Out*, I remember a time when, new in my position as a community worker, I wondered whether women’s troubling experiences in Montreal were perhaps idiosyncratic. I wondered whether refugee and immigrant people in other parts of Canada experienced any of the same challenges associated with HIV diagnosis through mandatory HIV testing. The answer, as I would come to find out, was yes.

Toronto’s Committee for Accessible AIDS Treatment had inquired into what happens to refugee, immigrant, and undocumented persons during the immigration medical examination after an HIV-positive diagnosis. The Réseau des chercheuses africaines (RECAF, Network of African Women Researchers), a now dissolved community-level organization in Toronto, had investigated health, immigration, and legal issues facing francophone women across Canada.<sup>15</sup> Results from both reports were familiar since they resembled events that the women in Montreal had described to me. Talking to the Committee for Accessible AIDS Treatment,<sup>16</sup> an HIV-positive applicant said that when the immigration doctor

called, “he said that there was a problem. He just told me [my HIV status]. I was depressed. I was shocked. I was in denial. So, it was like my head was going to, like, explode. What happened to me was the doctor, he calls me, and on the phone, he’s telling me, ‘You’re HIV-positive.’”

An employee of an Ontario-based AIDS service organization described the work of immigration doctors and people’s experiences with HIV testing in the medical examination.

It is mandatory already that [immigration doctors] have to do the pre- and post-testing counselling, but it’s not happening ... It’s in the policy, but it’s not happening. And ... there doesn’t seem to be anybody who is ensuring that it’s happening. So who’s overseeing these medical doctors to say, “Did pre- and post-test counselling happen? How did it happen and where were they referred?” And so, there needs to be some overseeing of that process. Because most of my clients say it didn’t happen. Or they got a phone call saying, “By the way, you’re positive.” And that’s it. And then they’re left with this news with no idea where to go. And then it starts them off with this feeling of going underground instead of sort of starting them off on the right note on where you can access ... giving them some really positive encouragement ... It starts off really bad. And then you’re picking up pieces for a long time. I think it should be mandatory that if they’re going to do the immigration medical, then they need to know how to deal with immigrants, they also need to know about pre- and post-test counselling, and they need to know where to refer them – that these things are very important.

A woman who learned that she was HIV-positive in the immigration medical examination was interviewed by the Réseau des chercheuses africaines.

*RECAF: Vous a-t-on fait passer des tests du VIH? Et combien de fois?*  
Were you asked to do HIV tests? How many times?

*Femme: Je ne me souviens pas que l’on m’ait dit à un moment donné du processus que je devais passer le test du sida. Je suis allée passer les*

*examens chez le médecin que mon avocat m'avait recommandé c'est tout. Il ne m'a pas dit qu'il me passait un test de sida. Au pays, je n'en ai pas passé non plus. Nous venions avec mes copines, je sortais de temps en temps avec un diplomate de l'ambassade du Canada là-bas au pays, c'est lui qui nous a refilé le visa sans problème et, voilà!*

I don't remember if I was told at some point in the process that I had to take an AIDS test. I went to do the tests at the doctor that my lawyer suggested. That's it. He didn't tell me that he was doing an AIDS test on me. Back home, I didn't have tests done either. Back home, my girlfriends and I used to go out with a diplomat from the Canadian embassy from time to time. He is the one who got us our Canadian visa, no problem. That's it!

Another woman's interview with the Réseau des chercheuses africaines went as follows:

*RECAF: Vous a-t-on fait passer des tests du VIH? Et combien de fois?*  
Were you asked to do HIV tests? How many times?

*Femme: Ô! Oui, vous voulez savoir combien de tests j'ai passé? Oké ... Quand je suis arrivée ici, on nous a encore fait passer le test. La première fois ce n'était pas concluant. La deuxième fois mon agent [de l'immigration] m'a demandé d'aller revoir le médecin chez qui j'avais passé les tests.*

Oh! You want to know how many tests I've had. Okay ... When I arrived here, they had us do another test. The first time, the test was inconclusive. The second time, my [immigration] agent told me to go back to the same doctor who had tested me.

*RECAF: Est-ce qu'un agent de l'immigration vous a posé des questions relatives au VIH/sida? Did an immigration agent ask you questions about HIV/AIDS?*

*F: Oui, des questions relatives à mon état de santé; si j'avais eu des relations à risques; combien de partenaires j'avais; si je connaissais le*

*statut sérologique de mon époux, et cetera. Je ne me souviens plus d'autres détails ... [Rires.] Vous savez, demander à une femme qui s'est échappée d'un pays en guerre si elle a eu des relations à risque, il faut plutôt lui demander si elle a subi des relations à risques ... C'est plus juste.*

Yes, questions about my health, whether I had had risky sex, how many partners I had had, if I knew my husband's HIV status, et cetera. I don't remember other details ... [Laughs.] You know, asking a woman who escaped civil war if she has had risky sex, the question should be whether she was *subjected* to risky sex ... That's more accurate.

RECAF: *Connaissez-vous votre état sérologique?* Do you know your HIV status?

F: *[Silence et soupir.] Oui, je connais mon état, je suis testée positive. [Larmes.] Je croyais que j'étais épargnée quand mon premier test était négatif dans le camp [de réfugiés]; arrivée ici, tous les tests qui ont été faits sont positifs. [Les pleurs s'intensifient.]*

[Silence and a sigh.] Yes, I know my status. I tested HIV-positive. [Tears.] I thought that I had been spared when my first test was negative in the [refugee] camp. Once here, all the tests that were done have been positive. [Crying intensifies.]

Juxtaposed with these emotionally charged first-hand accounts with HIV-related immigration processes and procedures were academic and bureaucratic representations of women's experiences.



The authors of an article published in 2004 in the *Canadian Journal of Public Health* report that mandatory immigration HIV testing “focuses on identifying the disease to expedite counselling and *referral* to appropriate services.”<sup>17</sup> Two years later, in the *International Journal of STD and AIDS*, an article appeared about “the first two years of an active, immigration medical screening programme for HIV antibodies in

applicants.”<sup>18</sup> The authors assert that “all applicants were counselled and gave informed consent to testing.” Interestingly, these are the only publicly available quasi-official articles detailing how the state understands its HIV-related policies to be implemented in practice. Since HIV-positive people’s lived experience was obviously dissonant with these claims, I was irritated and curious to find out why.

In a first instance, claims about *consent* practices, for example, could quickly be struck down. Since early 2002, when Canada’s federal immigration department inserted mandatory HIV testing into the immigration medical examination via a policy change, all immigrants applying to Canada for permanent residency (and some for temporary residency) have had no choice *but* to be screened for HIV. Thus, there is no informed consent process *per se*. In a second instance, the claims about *counselling* practices, in turn, were inexact at worst or in need of serious nuance at best. How things happen was neither as seamless nor as straightforward as portrayed in the academic articles. The professional work experiences that were associated with this policy by nurses, HIV doctors, social workers, and lawyers who had been my colleagues also told a different story.<sup>19</sup> In a third instance, there were grounds to investigate the claim about *referral* practices, namely that people were getting consistently referred to HIV clinics for care and that these referrals were unremarkable and happening without any notable incident.

In Montreal, a former nurse, an HIV doctor, a social worker, and lawyer colleagues all described sudden spikes in the numbers of people living with HIV who presented at their clinic in the first four months of 2002. Citizenship and Immigration Canada had not advised them that HIV testing was being added to the immigration medical examination. Their daily clinical work was directly affected by this policy change. They had to determine how to receive people and address their needs. They found themselves mobilizing to help new populations of people with whom they had little experience. Their new patients were from many different societies of the global south. The bodies of those who started coming to the clinic bore scars and carried within them unspeakable psychic wounds inflicted by social inequities of all sorts; my former colleagues despaired at their new patients’ bodily wounds and existential suffering.

Within the HIV-related counselling, referral, and consent practices alleged to be taking place in the medical examination was an entire universe of occurrences that was being completely erased by these authoritative claims. Given that the problems with these practices had been firmly established through people's personal and professional experiences, I wondered on what authority the authors had based their ideas.

In the 2006 article published in the *International Journal of STD and AIDS*, which asserts that "all applicants were counselled and gave informed consent to testing,"<sup>20</sup> a disclaimer reads that "opinions" are "prepared in personal capacity" and attributable only to the authors. Although this statement withdraws focus from state-level responsibility, the findings are authoritative. The article is printed in a peer-reviewed journal. Its authors, then "senior medical staff" of Citizenship and Immigration Canada, were responsible for upholding the policy of mandatory HIV testing, managing immigration physicians, and overseeing the state's medical officers. The role of the state medical officer in the immigration process is significant, since the medical officer's decision about an applicant's medical inadmissibility on health grounds directly informs the work of the visa or immigration officer who writes the applicant a decision letter. As state employees, the set of authors used databases created to monitor and track HIV-positive applicants. Employing quantitative logic, their reports organize statistical rates and distributions of "HIV cases" according to the *Immigration and Refugee Protection Act's* categories, denoting the bodily status of applicants – "immigrants," "irregular applicants," "refugees," and "Convention refugees" – grouped by geography and sex. Their analyses build on data and practices of the United Nations and the International Organization for Migration, namely epidemiological fact sheets, official statements, conventions, and protocols; on Canadian federal legislation, official lists, regulations, statutes, operational bulletins, and epidemiological studies; and on scholarly articles in medical and health journals focused on infectious disease, epidemiology, health promotion, and migration (several written by the same authors of the articles above published in 2004 in the *Canadian Journal of Public Health* and in 2006 in the *International Journal of STD and AIDS*).

The state's understanding of the services done by its immigration doctors was disembodied. The claims to facticity were divorced from people's lived experience. Applicants and their real-life presence were inferred. The circumstances of their lives were pre-empted. Produced instead were textual surrogates of carnal experience. As a direct consequence, human beings with HIV have been objectified. *They no longer exist as humans*. They have been reborn as bureaucratic categories. This distortion happens through "methods of representing people's activities, talk, relations, and thinking without the subjects who act, talk, relate, and think."<sup>21</sup>

Left unexplored and unchallenged, authoritative claims stand over and replace experiential knowledge of what happens to people subjected to the immigration medical examination and HIV-specific practices. Authoritative reports present a certain version of how things happen. The two articles in the 2004 *Canadian Journal of Public Health* and the 2006 *International Journal of STD and AIDS*, for example, were produced using audits of people's textual practices, so an immigration doctor's circling of or tick in a box beside the words "counselling provided" becomes a counselling *fact*, which then informs sets of statistics about counselling practices in the immigration medical examination. This is a problem when such presentations are at odds with how processes actually happen for people. Yet these versions are on record and stand as official versions. Their results are produced and reproduced in official publications of various sorts. They are accessible online and archived in virtual library catalogues to be read in professional magazines, academic journals, and scholarly conference proceedings. Because academics and their students refer to these texts, their results live on in the references cited in other sources. Policy makers all over the world take up the results. These actions are how authoritative accounts come to stand in and stand over *actual* events as they have occurred on the ground. This situation is a concern since authoritative accounts gloss over social complexity while obscuring our ability to see, learn, and organize in order to change the things that people (including ourselves) experience as problematic.

Although the data and findings presented in the two articles are, in all likelihood, correct in terms of their epidemiological grounding, the authors are able to tell us only a partial – and thus incomplete – story

of the implications of Canada's mandatory HIV testing. Neither of these pieces is able to provide insight into the lived implications of this policy for those whose HIV status is exposed, their families, the lawyers with whom they work, and the medical practitioners who diagnose them or for the other doctors, nurses, and social workers who will see them as patients at other moments in time and in other settings. It is necessary to empirically illuminate, nuance, and correct official policy accounts that are disconnected from people's lives. Otherwise, the risk is that such accounts, which are authoritative and in wide global circulation, will become the accepted representations and *evidence* that certain practices, procedures, and state-advised standards are being practised.

Learning about what produced this disjuncture – between people's experiences and knowledge of the world and the official or authoritative representations of these experiences and knowledge – was the impetus for this project. As an epistemological “line of fault” and a contested space between the inside and the outside of the “objective, bureaucratic domain of a politico-administrative régime,”<sup>22</sup> this disconnect also provided a material entry point to begin to lift – indeed, pry! – open the lid of the immigration system's bureaucratic black box.

In this book, I explicitly provide evidence of a distinctly plural and deliberately different kind about what happens within the social organization of immigrant people's experiences in relation to Canada's mandatory HIV testing.<sup>23</sup> Here, lived experience is foregrounded and knowledge is produced about and for people – in particular, those whose lives informed the empirical work upon which this book rests – in ways that humanize knowledge and put people, politics, and places in their social contexts. This book intends to fill out the picture of what happens in practices related to immigration medical screening. And so, how *are* things organized in the medical examination for people living with HIV? To answer this question, one needs to start by talking with and listening to people who have experienced the system first-hand.

### **Fieldwork: Institutional and Political Activist Ethnographies**

My ethnographic fieldwork consisted of observations, qualitatively organized open-ended interviews and focus groups, and analysis of an assortment of private and publicly available texts. I worked in Gatineau,

Montreal, Ottawa, and Toronto, and shifted between these cities over an eighteen-month period.

I carried out this project using theoretical, ontological, and methodological concepts from institutional ethnography, which is a distinctive Canadian school of sociological analysis based on Dorothy Smith's work on the social organization of knowledge.<sup>24</sup> I also drew from political activist ethnography, which is a Canadian school of sociological inquiry grounded in the contributions of George Smith.<sup>25</sup> These forms of scientific inquiry produce analyses of how ruling or governing gets done in the workings of the systems of media, law, medicine, health care, social services, education, and immigration. Because social life is not only produced and reproduced by texts, as described below, but also comes to be organized and coordinated by texts, they are highly important objects of study. In both inquiries, the skills and capacities of ethnographic practice – observing social life in all its variegated textures through immersion, talking with people in loose and organic ways for intentionally unpredetermined stretches of time, and being terribly curious to learn all that is humanly possible about local ways of doing things – are employed to make ruling arrangements explicit.<sup>26</sup> The goal is to document and analyze how these systems fit together to produce people's problematic and oppressive experiences. The objective is to gain awareness about these social and ruling relations through the analyses proffered. The specific promise of political activist ethnography is to furnish social scientific analyses that can be used as a base of empirical evidence in support of claims by individuals and social movements about the need for action.

I began by interviewing thirty-three people who described their experiences with HIV testing in the immigration medical examination after 2002 when mandatory HIV testing was introduced. We spoke primarily in English and French, and interpreters were crucial for assisting with people who preferred to speak in Amharic, Cantonese, Mandarin, or Mongolian. Very few people had English or French as their first language. The applicants were nationals of many countries, and brought to bear on this study their lived experience in the following countries: Botswana, Brazil, Burundi, Cameroon, Chad, China, Congo-Brazzaville, Egypt, Ethiopia, Italy, Ivory Coast, Kenya, Malaysia, Mexico,

Mongolia, Russia, Rwanda, Saint Vincent and the Grenadines, Sudan, Taiwan, the United Kingdom, the United States, Venezuela, and Zimbabwe (see [Figure 1](#)). The majority of the people I interviewed had applied from within the country as refugees or as family applicants – that is, as a spouse or common law partner. Throughout this book, I offer close ethnographic discussions of the circumstances and politics of people’s lives.

After these interviews were done, I met with twenty-eight people who had first-hand experiences of working professionally with applicants living with HIV or whose work was part of the bureaucracy within the Canadian immigration system. These interviewees included immigration lawyers, legal clerks, HIV and infectious-disease specialists, general practitioners serving as immigration doctors, clinical and community social workers, service providers working for AIDS service organizations, staff of temporary shelters, Public Health nurses and senior managers, medical doctors currently or formerly serving as senior advisors within the immigration medical program, and officers of the Canadian Border Services Agency. This book includes material from observational work conducted during proceedings of the Immigration and Refugee Board of Canada, in medical and legal clinic waiting rooms, and in offices of Citizenship and Immigration Canada. As I moved through all of these physical places where people lived and worked, I paid close ethnographic attention to everything happening around me so that I could write field notes at the end of each day.

The knowledge featured in this book is grounded in the *social standpoint*, or subject position, of people who were applying for permanent residency and living with HIV. Starting from within the standpoint of oppressed or exploited people reveals aspects of the social that are invisible from other social locations. This stance and its assumptions explicitly informed how I designed and maintained focus during the project, which then directly shaped my decision to write this book in the manner that I have.

In practice, this approach meant listening to people and learning about *embodied experience*, or the “lived entanglement of local biologies, social relations, politics, and culture.”<sup>27</sup> It committed me to making people’s *lived experience* – including awareness through bodily senses – the basis



**Figure 1** Interviewees' countries of origin

for studying the coordination of people's personal and professional lives related to HIV-specific immigration practices, thus valuing their *embodied knowledge* as an alternate to external authority. This undertaking involved expressly *not* taking as my "starting point ... the objectified subject of knowledge of social scientific discourse."<sup>28</sup> It meant making an "ontological shift"<sup>29</sup> to insist on seeing the world as brought about only through human action: your activities and those of your neighbours, my activities and those of my friends, and everyone's activities in homes and neighbourhoods everywhere. It meant rejecting abstract and speculative ways of knowing in order to transfer "agency away from concepts ... [and] back into the embodied knower."<sup>30</sup> Thus, social relations organizing what people do are analyzed rather than assumed. This approach marks the difference between analyzing social class as a category and as a social relation, which I am doing by evoking what people do cooperatively in the world they inhabit.

To be clear, this approach is not based on standpoint epistemology, which involves favouring the knowledge of one group of people over that of another. Knowledge from any subject position is partial; we know the world from our particular position in it. Given this limitation, experience is not a truth claim, and this book is not about individual experience, since people living with HIV are not per se the objects of research. Rather, experience "is a door through which the ethnographer goes to explicate the institutional processes that shape experience."<sup>31</sup> Put another way,

The significance of the voice of witness is that the witness has been there, has seen what happened. Witnesses have themselves lived the story of disaster and might themselves be victims. They can retell the story and unfold the event with first-hand authority. This does not mean that witnesses, just because they are insiders, possess the only authentic approach. The witness's narrative is only one of many, albeit one less heard.<sup>32</sup>

Throughout the fieldwork process, I also gathered publicly available texts issued by federal and provincial levels of government. In addition,

I used responses from personal requests and those made by colleagues for access to information in the federal immigration department's HIV database. Other data sources included applicants' personal immigration documents, which I discussed in situ with them. My attention was drawn to how state employees and my interlocutors developed and worked with, talked about, and circulated these texts.

Standardizing messages are communicated by texts such as the *Immigration and Refugee Protection Act* and its companion regulations, the policy on mandatory HIV testing and its resulting HIV-specific directives, handbooks prepared for immigration doctors and other publicly available materials published by Citizenship and Immigration Canada, redacted responses to requests for access to information in applicants' immigration paperwork, and my correspondence with people I interviewed and spoke with. These homogenizing messages are reproducible as material artifacts, which inform how people then do their work. People's textual practices – how they create, use, copy, store, share, or refer to texts – are observable and traceable, providing the “stuff” upon which I have based the analytic heavy lifting done in this book. Such texts are reproducible, appear in many places simultaneously, and are “like a central nervous system running through and coordinating different sites.”<sup>33</sup> It is this process of coordinating that links people's immediate practices with people and practices happening well beyond this immediacy. And it is here, in how things are coordinated, that ruling, regulating, and governing *happen*. When we can explain how textual coordination occurs, we can understand how society works and how people's experiences arise.

Texts are interdependent and relate to each other in hierarchal order. “Higher level texts establish the frames and concepts that control and shape lower-level texts.”<sup>34</sup> As the apical text, the *Immigration and Refugee Protection Act* governs the Canadian immigration system. All immigration-related texts, and what people do with them, are designed to comply with the language and ideas shaping the instructions that are featured in this legislation. I attended to how, where, why, when, and by whom texts were created, used, shared, and with what consequences for people. In other words, I did *not* orient to or treat texts as freestanding objects separate from the places and politics of people's practices.

For example, there is a battery of HIV-specific practices occurring inside and outside of Canada. The sites where these practices take place are all connected to each other through the textual practices that applicants, immigration doctors, state employees, lawyers, and others enact in concert with one another. Official texts produced by the immigration department are inscribed with the logic and priorities of Canadian immigration texts. Official texts communicate particular forms of knowledge about HIV that, in turn, require these actors to interact with HIV-positive people and make decisions about the latter's medical inadmissibility in specific and sanctioned ways.

### **Immigration Application Health Work**

I have organized this book around my empirical finding that preparing a permanent residency application is an enormous amount of *work*. Here, work encompasses all that people do “that takes some effort and time, that they mean to do, that relies on definite resources, and [that] is organized to coordinate in some way with the work of others.”<sup>35</sup> Preparing to be medically examined, receiving the news that one is HIV-positive, and learning how and whether this status will impact on one's chances of successfully settling in Canada are examples of what I am naming and deploying as *immigration application health work* as a social process.

I used this concept of work as an “empirically empty term” and filled it with descriptions of the activities and practices undertaken by people during their application process.<sup>36</sup> As I learned, great amounts of effort, time, and resources are required of applicants. People do various kinds of work, including the work of *doctoring*, the work of *responding to being singled out*, and the work of *lawyering*. They must get hold of sundry texts, which they are required to make sense of, fill out, and submit on time. They must wait (and wait some more) for responses from doctors, lawyers, and state officials about their immigration paperwork. (All of these things are done while people are adjusting to the demands and difficulties of receiving a diagnosis of incurable disease.) Applicants jump to attention. They do what others ask of them alone or with help from others, online or in person, in Canada or beyond its borders, in English, French, their mother tongue, or the lingua franca of their society in the global south.

In practice, people's immigration application health work occurs over a long time. It is taxing emotionally, financially, and in many other ways because it is high-stakes. Acting in accordance with the system requires a lot of skill and scrupulous planning that happens inside and outside of Canada. It demands that people somehow get used to having little to no control over what will happen to them. In many ways, it requires that people find the courage to put big parts of their lives on hold until institutional decisions about them and their families are made.

An astonishing number of people are under the employ of the immigration system. It is a key Canadian social institution. As an institutional system, it employs and contracts a swell of people inside and outside of Canada. For example, there are, at the time of writing, 2,900 immigration doctors and radiologists worldwide who carry out medical examinations and interpret chest X-rays as state contractors. The immigration doctor submits a medical file on each applicant, there are medical officers who receive and are charged with processing these medical files, and there are senior civil servants who consult, study, and draw up policy within the bureaucracy. The system also generates considerable revenue for a range of professionals, including lawyers and immigration consultants in private practice inside and outside of Canada who prepare, polish, and present applicants' storylines, upon which their clients are assessed as admissible or not.

These examples of formal labour force participation exist directly because of, are entirely supported by, and fully rely on the *immigration application health work* – as understood and used in the ways described above – of people such as those who appear in the pages of this book. Their work experiences and processes are *totally invisible* unless ushered into the spotlight, as I do in these pages.

### **Medical and Legal Borderlands**

As an investigation into the social organization of knowledge using theoretical, ontological, and methodological guidance from institutional and political activist ethnographies, *Screening Out* contributes to the discipline of sociology. My broad scholarly aim is to contribute to a distinctive Canadian school of sociological scholarship that has been

articulated as critical social science perspectives on HIV/AIDS. This line of work is grounded in the assumption that to respond to this epidemic, deep reflection on questions of epistemology is needed; that is, we need to reflect on “what we know, how we know it, and the relationship between knowledge and action ... including the knowledge used to justify funding decisions, to develop policy, to inform community education, and to organize the delivery of health services.”<sup>37</sup>

I use the term “critical social sciences” to refer to a broad range of work that is conversant with developments in contemporary theory, methods, and practices in the social sciences. “Critical social science research calls into question the processes, limitations, and effects of practices that govern people’s lives and seeks to contribute to contemporary struggles against social injustice, inequality, human suffering, and oppression.”<sup>38</sup> I have decided to retain the presence of the word “critical,” doing so neither unknowingly nor smugly, so as to ensure that from the get-go, the reader understands where this book belongs and does not belong. This positioning of the book is very important precisely to distinguish its mode of inquiry from the approaches that predominate in the research practices of both the health sciences and the HIV field. This book is *not* a bedfellow of these approaches.

As I am a sociologist, the vein of scholarship concerned with the medico-legal borderlands has been a highly stimulating organizer of my thoughts and actions. This book contributes to this family of inquiry. My understanding and application of these medico-legal borderlands have as their point of departure the scholarly contributions of sociologists Stefan Timmermans and Jonathan Gabe.<sup>39</sup> This double-barrelled concept refers to spaces of professional practice where the institutions of law and policy, medicine and health care, and social services exist side by side and also overlap. The analytic project is to harness our close, ethnographic attention to what happens in these various sites. The implications of these knowledge relations are the focus of attention. Inquiries within the borderlands of medico-legal spaces and places of investigation illuminate the presence and functioning of underexplored and frequently taken-for-granted forms of social control and governance, policy and practice, communication and discourse, and subjectivity and lived experience.<sup>40</sup>

A second thing that this book is *not* is an individual-level critique of state functionaries, bureaucrats, and contractors doing immigration medical work and HIV-specific work for the state. Neither is this analysis an individual-level critique of professionals – such as doctors, lawyers, and immigration consultants – whose work and bank accounts are reliant on the immigration application health work of this book’s protagonists who are permanent residency applicants living with HIV. At the same time, the analysis demonstrates – *without a doubt* – that injustices are happening systematically across time and place through state-related, HIV-specific immigration practices, including serious injuries for applicants in the presence and absence of HIV-specific forms of care and service. For this reason, I claim that corrective action at institutional places to prevent avoidable injustices and injuries is long overdue and thus urgent.

*Screening Out* fulfills the aim and objective of institutional ethnography to analyze and report on how ruling or governing systems – media, legal, medical, educational, and immigration – work together to produce people’s problematic and oppressive experiences. Thus, people can gain awareness through the analysis rendered in this book. It also delivers on political activist ethnography’s promise to furnish social scientific analyses that can be used as a base of empirical evidence supporting individual and social movement claims about the need for action.

### **Narrative-Driven Political Sociology**

*Screening Out* is written as an ethnographic story. It is rich in contextual detail about people, places, and politics. In adopting a narrative form, I was motivated by the idea that, since everyone likes a riveting story, everyone can learn from a captivating story. This is such a story.

The protagonist, Martha, is a black woman born in sub-Saharan Africa. Like all the given or proper names in this book, hers is a pseudonym. This narrative-driven analysis develops out of her standpoint, and the story told unfolds from within the events of her application for Canadian permanent residency. Her main interlocutor is named Meron, a doctor of western European descent who is in his mid-sixties and trained in general medicine. He also has an immigration medical practice where he carries out immigration medical examinations as an

additional source of income. Dr. Meron is a character I created based on what I learned about the practice of immigration doctoring through my personal interactions with immigration doctors and persons with HIV. The events, intrigue, and mounting tension between Martha and Dr. Meron occur within and because of the immigration medical examination and the HIV-related practices that either happen or do not happen there. The book's rhetorical style involves alternating between experience, explication, and engagement with other social scientists' ideas. In this way, I have a presence alongside that of Martha, Dr. Meron, and myriad others.

In this book, I assigned names to all speakers so that the reader can distinguish among them. The descriptions and analyses are based on real life events as Martha, Dr. Meron, and others lived them. The rhetorical choice of using this type of narrative strategy is analytically valuable for at least two reasons. For one thing, people's experiences and the social relations that organize them are generalizable beyond any single account, as is my analysis of them. Consequently, the findings and claims about what goes right and wrong for people, and about what changes are needed to the immigration system on this basis, are empirically supported. For another thing, this type of narrative strategy can help the reader to pivot from an individual-level focus to an organizational-level focus to learn about how people's HIV-related experiences are being produced institutionally and about the consequences for them and others. Ultimately, through back-and-forth exchanges and my analysis of these exchanges, a narrative and counter-narrative about the production, organization, and circulation of HIV-related knowledge in the Canadian immigration system emerge.

Arriving at the point of being able to see the forest for the trees within my own extensive corpus of data and then, much later, being ready to harness my stamina in order to sit down and write up these data in ethnographic narrative story form happened over time and through additional, tailored training. Not only did I want to get things right out of respect for people by representing my interlocutors and the situations of their lives in such a way that when or if they take this book in hand, they will recognize themselves and their experiences, but I also wanted to offer these same people the opportunity to learn about how the

very tensions and contradictions that they confronted and described to me are organized to occur in the first place. Being able to show, to tell, and to answer this *how* question was at the root of the project that gave rise to this book.



Out of respect for my interlocutors and to set myself up to answer the *how* question using ethnographic form, I looked for ideas about communicating one's social scientific results as narrative. I began by studying sociologist Timothy Diamond's approach in *Making Gray Gold: Narratives of Nursing Home Care*.<sup>41</sup> This is a masterful institutional ethnography of the organization of personal and professional life in nursing homes in the United States. Importantly, because of his analytic focus on the imbrications of the social and ruling relations that organize these places within market interests, his results and their implications extend much more deeply and broadly into and across many national borders. It is one of the most incisive and compelling books of political sociology that I have had the good fortune to read.

I also read some exemplary Canadian work on the political economy of health care for insight into foregrounding narrative to tell a political story. In *A Labour of Liberation*, physician Baijayanta Mukhopadhyay laments that his doctoring work is organized by the priorities of what he calls institutionalized medicine, arguing that the only way to give and receive care that matters is by decentralizing health care and wresting health knowledge away from clinical control.<sup>42</sup> And, for how to write in the soulful spaces where one's life joins with the lives of others we care about who are dying or ill, I looked to largely, yet not exclusively, Canadian literature in the medical humanities. Abraham Verghese's *My Own Country: A Doctor's Story*, set in eastern Tennessee in the 1990s, is both a doctor's tribute to the women and men with AIDS and their families who were his patients and a treatise for tolerance and compassion. He skilfully links the lives of many people together with his own, developing a powerful single story for the ages.<sup>43</sup> In her novel *Debout en clair-obscur* (Standing in the Shadows), set in and between Ontario and Quebec, Laurette Lévy develops a character named Béatrice. It is from the latter's position that Lévy carefully deliberates on her character's

gendered experiences of being diagnosed with HIV and figuring out life with a new biosocial identity.<sup>44</sup>

Finally, I read and watched Canadian works of ethnography in the area of migration studies for ideas about how to represent competing knowledge claims as narrative. In the book *Recounting Migration: Political Narratives of Congolese Young People in Uganda*, political scientist Christina Clark-Kazak explores the lives of young people who are forced migrants or refugees in Uganda who have “ten very different narratives of migration.”<sup>45</sup> She sets youth’s interpretations of the situations of their lives – how they work to shape decision-making processes in their homes and communities and in policy realms – in juxtaposition and productive tension with bureaucratic ways of knowing and representing these same social situations. And in the short film *El Immigrant*, art historian Lina El-Shamy takes a full-frontal approach to the depiction of social suffering and pain. She uses the experience of losing fluency in one’s mother tongue after immigrating permanently to Canada to discuss her family’s regret, which is shaped by challenges with the organization of formal and informal life in their new society.<sup>46</sup> She writes that “identity is not just an abstract, internalized feeling; it is a lived, material reality: the languages our tongues (are allowed to) speak, the professions we (are allowed to) practice, and the alienation resulting from the physical and linguistic distances created by generations.”<sup>47</sup> Both of these works are illuminating for how they correct misconceptions that migrating ushers in nothing but opportunity for people – ideas nestled within claims that migrants should be grateful to adopted states for receiving them in the first place.

All of these fine contributions influenced the ways that I approached writing this book. As these authors have done, I have set up a specific sort of relation between author, text, and reader, one whereby emotion and personal meaning are evoked. For this reason, the reader should expect and prepare to encounter and reflect on issues of concern that are as deeply personal as they are societal.

## Chapters

The first chapter, “‘Good Chickens’ and ‘Bad Chickens,’” commences with Martha, as protagonist, accepting my invitation to be interviewed

about her permanent residency application from her standpoint as a person with HIV. Threaded within the events of her process are those of other HIV-positive immigrant and refugee persons. The purpose of this chapter is to introduce context about how applying to become a permanent resident is socially organized for people living with HIV. I do so by letting readers get to know Martha and her fellow applicants personally. The reader gains appreciation for the circumstances of people's lives both before they come to Canada and after they are in the country. The chapter moves from a university dormitory in Russia to a single-room apartment in Canada and into people's kitchens and family rooms in Montreal. It places readers' bottoms in the seats of a university lecture hall, a refugee hearing, and an immigration interview. The reader has no choice *but* to walk in the footsteps of HIV-positive applicants as they are instructed by influential others to accept being classified informally as "Bad Chickens" and formally as disabled persons, to expect to face unemployment and to accept menial jobs, and to lie in writing and orally in official situations.

In this first chapter, the reader pivots from the biographical to the institutional. In the biographical context, immigrating is skilful and taxing embodied work that affects entire families, and interlocutors hold themselves accountable to a constellation of people since their lives happen within collectivist notions of kinship. In the institutional context, immigrants need to accept being classified and medically acted upon in particular ways; they are associated with health, safety, and financial risk, they see and talk about themselves from within the state's fixation with cost-oriented reasoning and health-based exclusion, and they are seen and talked about in these ways, preventing the state from knowing them in any other way. I discuss the social organization of applying to Canada as a person with HIV through a historically informed description of how the immigration system has been set up to medically and legally govern and exclude applicants with ailments as an uninterrupted pattern that began in the late nineteenth century and persists today.<sup>48</sup> A key moment in this history, and the primary reason for my work, was the enactment of a new HIV-specific policy regime in 2002 when Canada's federal immigration department inserted mandatory HIV testing into the immigration medical examination.

The second chapter, “It would be great to have you move to Canada,” starts with Martha learning that the next step in her immigration application necessitates making an appointment to see an immigration doctor for a medical examination. The aim of this chapter is to contextualize how being medically examined is socially organized for people living with HIV. It focuses on what testing HIV-positive through mandatory HIV screening in the medical examination looks and feels like in various societal contexts around the world, including inside of Canada, from the standpoint of Martha and her fellow applicants. Supplementing these perspectives are those of Dr. Meron, an immigration doctor, who describes his HIV-specific work in the medical examination before and after he diagnoses an applicant with HIV. The reader sees what applicants do not initially recognize when they meet him: that his doctoring in this specific instance is administrative not therapeutic, which means that his clinical reasoning and judgment are displaced.

As the chapter shifts between foreign and domestic medical offices and waiting rooms, HIV-positive chat rooms and consultations with lawyers, and the workplaces of Citizenship and Immigration Canada and the Canadian Border Services Agency, a portrait emerges of how a positive diagnosis adds a layer of complexity to the process of people’s immigration application health work. Readers listen to people’s talk (and silence) in the medical examination and witness how they wait (and wait some more). Through these experiences, readers can imagine (if they dare) what it feels like for people to acquiesce to demands made of them for what are often years at a time in the hope of immigrating to Canada. Such demands include submitting to whatever medical screening and health-related processes are asked of them.

In this chapter, the reader again transitions from the biographical to the institutional. In the biographical context, we see one-on-one interactions between applicants and doctors in the medical examination, and in the institutional context, medical files tagged “abnormal” and tattooed “problematic” create the textual basis for the state to interpret applicants as abnormal and problematic across time and place within the immigration system. I discuss the social organization of the medical examination for people living with HIV by examining how a positive test result entered into a medical file is taken up through disease-specific professional and

bureaucratic practices. These practices produce the documented snares that Martha and others experience. They also produce the interpretive frame that makes it possible for people living with HIV to be acted upon in unique and prejudicial ways in the Canadian immigration system.

The third chapter, “It was just a form. I did not get a copy,” opens with Martha receiving a telephone call from the immigration doctor’s office. She needs to return for a follow-up appointment. She sits and waits for the doctor, yet she already knows what he has on his mind: she is HIV-positive. The purpose of this chapter is to explicate how being cared for and served by the immigration doctor is socially organized for people living with HIV. The previous chapter begins an analysis of immigration doctoring work. Here, I pick up and pull this analytic thread, focusing on how doctors’ HIV-specific textual practices connect with the HIV-specific textual practices of bureaucrats and other professionals. Importantly, I make explicit the rhetorical or ideological ends that the coordinated sum of these textual practices achieves in the Canadian immigration system, while also making visible the consequences of these arrangements both for people living with HIV and for physicians in the role of an immigration doctor.

Narratively, this chapter is structured as a back-and-forth dialogue between Dr. Meron and me. Martha and her fellow applicants, and others whose professional lives fasten them to the Canadian immigration system, likewise have an active presence. Like a fly on the wall, the reader accompanies Martha and others into medical examinations in various Canadian cities, and also Khartoum, Moscow, Nairobi, and São Paulo, for example, experiencing what happens there on the heels of diagnosis. Readers’ hands are placed on the *Immigration and Refugee Protection Act* and successive versions of the state’s *Handbook for Designated Medical Practitioners*, on the “Acknowledgement of HIV Post-Test Counselling” form, and on redacted and nonredacted versions of the policy mandating HIV testing.

In this chapter, the reader once more turns from the biographical to the institutional. The biographical context includes consent, counseling, and referral practices that either happen or do not happen in immigration doctoring practices, as per people’s lived experiences, and

the institutional context consists of the state's rhetorical or ideological representation of what happens in the medical examination through the doctor's work, as per textual representations of people's lived experiences. I discuss the social organization of the care and service that the immigration doctor provides for people living with HIV, and explain the HIV-specific practices that, among other implications, heighten people's vulnerability and expose them to exceptional burdens and harms inside and outside of Canada.

The concluding chapter begins with Martha answering the telephone. The caller is from the Canadian embassy in Moscow. Martha anticipates the announcement of whether she has been accepted for permanent immigration. Since she has no idea about the odds of a "yes" rather than a "no," she braces herself. Whatever the state's decision about her, it will have ripple effects for her and those who depend on her. Has she been accepted into Canada as a permanent resident? Or has she been refused because of the excessive criteria? When we met in Montreal, where we were both living at the time, I asked about her personal situation. Was she living her life *au Québec* without official documents to stay? Had she been accepted but overstayed when her visa expired, finding work *au noir*?

It is in the Conclusion, on the last pages of *Screening Out*, that the reader learns how Martha's immigration application process turned out. The purpose of this concluding chapter is to summarize the analysis and findings generated by this book.

As a social researcher, since I am tasked with producing original scholarship, taking part in and stimulating public debate as a "public sociologist,"<sup>49</sup> speaking from my expertise, and making claims supported by research evidence, I conclude by offering two concrete recommendations for structural-level changes. Both to support social change and as an expression of "ethical militancy," I offer actionable, evidence-informed suggestions for legal and policy reform.<sup>50</sup> Ultimately, where implemented, these recommendations and suggestions can attenuate the effects of systematically occurring harms that are being produced through HIV-specific institutional practices happening within the Canadian immigration system inside and outside of Canada.

### Notes to the Reader

To prepare and assist the reader, I offer the following four notes about distinctive linguistic, research, and stylistic choices that shaped how I organized this book.

Since the primary languages spoken during fieldwork were English and French in equal measure, where I quote people directly, I have done so in the language in which they or their interpreter addressed me. And where my shared language with people was French, I have prepared English translations. I have placed the latter after the italicized original in the body of the narrative. This choice was made out of respect for the people I interviewed, and it expresses my personal preference and political resolve, which happen to join with the research practice of Canadian and Quebec scholarship in socio-linguistic anthropology, where there is an insistence on preserving language as it was “used in its social context.”<sup>51</sup>

What people told me, what I saw at refugee hearings, what is written down in official texts, what is posted online, and what official forms interlocutors were asked to fill out *are* the data. For this reason, I have made generous use of interviews, observations, field notes, correspondence, and publicly available scripts to help me tell the story. This decision also reflects my commitment to ensuring that bodies and their practices, presences, and experiences are always foregrounded and never swallowed up in the analysis. I have contextualized excerpts so that readers understand how I am inviting their interpretation. Within passages of direct quotation, where I have italicized words for emphasis, I indicate that I have done so. Unless otherwise stated, italics appearing within excerpts communicate people’s own verbal inflections.

I had initially thought of including official forms published by the federal immigration department as appendices. I have found this approach valuable analytically in published examples of institutional ethnographic studies, especially when one is designing a study or teaching this mode of inquiry.<sup>52</sup> However, these forms change over time, mirroring changes to the name of the immigration department itself. For example, when I began this study, the department was called Citizenship and Immigration Canada. At this writing, it is called Immigration, Refugees and Citizenship Canada.<sup>53</sup> For the reader’s ease,

I have chosen to use the former, shorter name consistently. And rather than including texts, I have provided references to the specific versions of the official texts that I used. Many of these are available online. As for official texts no longer or not publicly available – access to information requests, presentation slides, and materials produced and shared with me in paper and the like – I have indicated whether these are in my possession.

Lastly, since I want this book to capture the interest of general readers in addition to scholarly ones, to stimulate ease of reading, I have made two moves. I have used bibliographic notes rather than in-text citations, and I have included little discursive content in the notes, saying what needs to be said in the book's body. The bibliographic notes will appeal to readers wanting to dig into the secondary sources. I have also used section breaks rather than subheadings throughout the following chapters as the means to group ideas. The strength and value of this approach were reconfirmed for me after reading ethnographic research in sociolinguistic anthropology.<sup>54</sup>

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