Picturing Public Health Surveillance:
Tracing the Material Dimensions of Information
in Ontario’s Public Health System

By

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Abstract

The aim of this dissertation is to explore public health surveillance from a surveillance studies perspective. The public health system in Ontario, Canada, provides an ideal setting for such exploration, especially because of initiatives that have been undertaken in the wake of the 2003 outbreak of Severe Acute Respiratory Syndrome (SARS). Post-SARS, local public health practice in Ontario has been increasingly overtaken by a system-wide imperative that seeks to transform surveillance through investment in large-scale, information technology (IT). By critiquing the dominant conception of information in social scientific, public health and medical care discourse, and by exploring the increasing integration of large-scale IT into public health surveillance practice, this dissertation considers the uncertain trade-offs involved in the contemporary movement towards large-scale, IT-mediated public health surveillance systems. The theoretical framework that guides this line of inquiry emerges out of a Deleuzian-Latourian tradition in surveillance studies. This framework foregrounds the material assemblages, the network of people, machines, microbes, maladies, organizations, and so on, that make public health surveillance possible. Material assemblages tend to be submerged from view, even marginalized, by large-scale, IT-mediated surveillance systems. Such systems strive to immaterialize information. They are organized according to an immaterial conception of information. This arrangement fosters the marginalization of the material dimensions of information.

In order to empirically specify the heterogeneity of the marginalized material assemblages that make public health surveillance possible, 64 semi-structured, open-ended interviews were conducted with public health professionals and patients. The main findings of this dissertation are explained using the example of communicable-disease surveillance,
and particularly HIV/AIDS surveillance. These findings highlight the systemic nature of marginalization that accompanies the increasing automation of public health surveillance. They suggest the need to question whether large-scale, IT-mediated surveillance is optimally configured, not merely for the challenges posed by disease, but also for the broader provision of public health services.
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Outside institutional public health, and looking in, the concept of *public health surveillance* appears enigmatic. One of the reasons for this has to do with the fact that surveillance, in a public health setting, is disproportionately focused on disease. In this sense, the phrase *public health surveillance* is a misnomer. Notwithstanding the occasional effort to survey factors related to broader ‘determinants of health,’ most of what is commonly meant by the phrase would be better described as *disease surveillance*. There is, thus, a productive ambiguity at the heart of public health surveillance. For public health, this ambiguity is productive because it facilitates the mobilization of resources. Who, after all, would be against surveillance undertaken in the name of the public’s health? Social scientists, too, can discover a productive ambiguity in the concept of *public health surveillance* precisely because the nature of the (imagined) public’s health is left unstated.

While this ambiguity provokes productive questions, it also poses descriptive challenges. What counts as *public health surveillance*? I take a broad view of this concept and enroll a range of different actors and practices that are not normally considered in public health discourse on surveillance. Consequently, my descriptions may not always resonate with the views held by my study-participants, especially those who work in public health. Nevertheless, my hope is that my outsider’s perspective is fresh, and that those who took the time to speak with me will find new insights in what follows.
Chapter 1: Introduction

March, April, May, and June of 2003 were, in the words of the authors of *Learning from SARS*, “four extraordinary months in the history of Canadian public health…” (Canada, NAC 2003: 23). As this report went to press, the outbreak of Severe Acute Respiratory Syndrome (SARS) had directly touched over 100 Canadians, killing 44 of them. Globally, the SARS coronavirus is thought to have infected some 8000, causing nearly 800 deaths before it was contained. In the words of one prominent commentator: “SARS shook the world. By some standards, the first emerging and readily transmissible disease of the 21st century was not a big killer, but it caused more fear and social disruption than any other outbreak of our time” (Omi 2006: vii).

Indeed, the SARS outbreak had a transformative effect on the Canadian public health and medical care systems. In the aftermath of the crisis, governments at all levels made a flurry of commitments to strengthen public health and medical care infrastructure. Among these was the oft repeated promise to create a comprehensive public health surveillance system, supported by the latest networked information technology (IT). In 2004, the Canadian federal government committed $100 million towards the development and implementation of “a high quality, real-time public health surveillance system to assist in the timely identification of infectious disease outbreaks such as SARS” (Canada, DoF 2004). In Ontario, where the SARS outbreak had been most severe, the provincial government faced significant pressure to rapidly put such a system in place. During 2005, it spent $25 million to implement the *integrated Public Health Information System* (iPHIS) in each of the province’s health units. The goal of this initiative was to enable public health units to “better trace the path of infectious diseases and manage quarantines” (Ontario, MHLTC 2004: 7).
The iPHIS initiative was a central component of the effort to strengthen health system preparedness. “Critical to achieving our vision,” Ontario’s Ministry of Health stated, “will be investing in a technologically advanced infrastructure for health system preparedness, including state-of-the-art surveillance, communication systems as well as updated protocols and guidelines” (ibid. 10). This position – that state-of-the-art IT is a necessary condition for health system preparedness – is widely held. After SARS subsided, many public health professionals voiced the opinion that the outbreak was exacerbated by Ontario’s sub-optimal IT. Toronto’s (then) chief medical officer of health remarked that, during the SARS crisis, public health workers were “using nineteenth century tools to fight a twenty-first century disease” (Dr. Sheela Basrur, cited in: Canada, NAC 2003: 29). The deeper question underpinning Dr. Basrur’s remark, however, is whether contemporary public health, let alone its tools, is up to the challenges posed by twenty-first century disease?

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Concerns over the threats posed by twenty-first century disease have dominated public health discourse since at least the early 1990s. These revolve around the idea that heretofore unknown pathogens will exploit the increasingly comprehensive reach of global trade and travel and infect naïve populations. Evoking the novelty of SARS, the scale of HIV/AIDS, and the gruesome exoticness of a host of tropical diseases like Ebola, twenty-first century disease provokes considerable anxiety and motivates the development of a coherent global response. At the same time, the global distributions of wealth and health are strikingly uneven, seemingly precluding bottom-up efforts to secure populations against communicable disease. Insofar as global disease surveillance promises a top-down overview
of the distribution and determinants of disease, as well as a logic for directing scarce resources, it appears to offer a pragmatic solution.

If SARS, standing on the shoulders of previous outbreaks, presented the global public health community with a ‘natural’ reason to fortify disease surveillance, the 2001 anthrax attacks in the United States (US) suggested another purpose and rationale for disease surveillance. Biosecurity concerns have, since at least the advent of the cold-war, been entwined with the desire for effective disease surveillance. However, as the global political system has transformed from a bi-polar one to an increasingly imperial and poly-centric one, the spectre of bioterrorism has come unbridled from the international system of sovereign states. The more bioterror threats can come from anywhere, the more necessary, it seems, for disease surveillance to be globally comprehensive.¹

In 2005, on the heels of the SARS outbreak and in the wake of the 2001 bioterror attacks in the US, member states of the World Health Organization (WHO) adopted a new set of International Health Regulations (IHRs). These new regulations compel member states to strengthen disease surveillance. Crucially, they also empower the WHO to circumvent member-state reporting structures. The new IHRs thus represent the WHO’s attempt “to harness new information technologies,” and thereby change “the context for State calculations about whether to report or try to cover up an outbreak” (Fidler 2005: 22).

While the effects of the new IHRs remain to be seen, one consequence may be an IT race amongst states and supra-national actors, as they vie to buttress arguments over who has the most accurate disease information. Hence, it is not only in Canada that public health officials are looking to IT as a solution to the challenges posed by twenty-first century disease.
System-wide, IT-mediated surveillance seems to promise a kind of virtual (if not actual) protection; it is an ideal-typical solution in a public health system *there of necessity, if not necessarily there*. Hence, while surveillance can certainly have utility in any public health setting, the coming dominance of public health by surveillance (the equation of *public health* with *surveillance*) becomes more likely as public health systems increasingly pick up the slack from crumbling or non-existent primary care systems, and as they become increasingly involved in the procurement of national security.

Under such conditions, public health officials face numerous crises. They are put under enormous pressure to strike the right balance with respect to their interventions. In the face of such pressure there is, perhaps unsurprisingly, an optimistic embrace of IT as a key tool for evidence-based decision making. This optimism emanates from medical care and public health discourse. Indeed, the attempt to create a real-time, high quality public health surveillance system, and to do so on national and international scales through massive investment in IT, is widely believed to be both necessary and necessarily good.

In this dissertation, I question whether the investment in large-scale IT is necessarily compatible with public health surveillance, and whether, in turn, such public health surveillance is always in the interest of the public’s health. I explore the consequences of moving to increasingly large-scale, increasingly IT-mediated surveillance systems. I do so with an empirical focus on the transformation of public health surveillance in Ontario, especially following the introduction of iPHIS. Ontario’s experiences with iPHIS have proven instructive, not least because iPHIS failed to live up to expectations that it would be an effective real-time surveillance system. In light of the fact that the Ontario government is poised to replace iPHIS with a new system “at an estimated cost of $60 million, pending
funding approval” (Ontario, AG 2007: 293), it is time to reflect upon just what is at stake in the development of large-scale IT meant to foster surveillance in the service of public health.

Although this kind of reflection is scarcely evident in policy discourse on public health, many who work in public health have been quietly (and sometimes not so quietly) raising such questions. A conversation I had with a doctor, working in the area of HIV/AIDS surveillance, illustrates the necessity of following this line of inquiry. It also suggests a level of frustration that such questions, and the critical process of self-evaluation that they imply, are given seemingly little consideration where instrumental rationalities dominate:

I 47: You know, we’ve been having a lot of difficulty working with the system.

MF: Are you talking about iPHIS now?

I 47: I’m talking about iPHIS, and I’m talking about the Ministerial surveillance program. I don’t even know where to start. It’s a major, major problem. First of all, iPHIS is creating all kinds of challenges. I don’t know how it happened. Everybody was saying this was the latest thing since sliced bread, and how wonderful it was. It turns out, for example, with relation to HIV, as you may have already heard, they somehow or another are unable to collect risk factors. In an obvious way, that’s totally ridiculous. You know, it’s a mistake that should never have been made. It was total mismanagement, I’m not sure who was responsible, I don’t even care, but, clearly, it was a major, major mistake to set up a system that couldn’t collect that information. […] That’s on one plane. On another plane – I don’t know what’s going on there – but we have not gotten a very collaborative attitude from the people who have taken over the surveillance system. You know, they don’t have a service mentality. They don’t have the enthusiasm, the expertise, the experience… […] They’ve got the wrong attitude, the wrong culture. They’re in the wrong place, as far as I’m concerned.
The concerns raised by this doctor beg key questions about the purposes of public health surveillance. In the spirit of these critical concerns, I now introduce the main thesis of this dissertation.

**Thesis Statement**

By examining public health surveillance in Ontario, by exploring the material dimensions of public health information, this dissertation sheds light on the local heterogeneity that stands to be flattened out by the increasing integration of large-scale, IT-mediated public health surveillance. Local heterogeneity is at risk of being flattened, I contend, because it is increasingly subsumed under a particular mode of public health surveillance. This mode of public health surveillance is embodied in large-scale, IT-mediated data collection efforts that are oriented by what I call an *immaterial conception of information*. Immaterial conceptions of information hold information to be immaterial, disembodied and disembedded.

The main thesis of this dissertation is that, with respect to public health surveillance, an over-arching immaterial conception of information imbues some kinds of information with more import, for surveillance, than other kinds of information. Specifically, this conception encourages the collection of abstract, digitized signifiers while simultaneously marginalizing other kinds of embodied, contextual information. Indeed, the pursuit of immaterial information for public health surveillance produces a dominant but superficial epidemiology at the expense of other potentially more effective epidemiologies.

Moreover, to the extent that public health surveillance is organized by an immaterial conception of information, it will likely remain an inadequate response not just to communicable disease, but also to the broader, underlying conditions that determine health. For example, HIV-disease signifies differently depending on where one lives, be it Toronto
or Timmins (not to mention the host of other places where HIV/AIDS is deemed to be endemic). These different significations are flattened out by the increasing investment – financial, intellectual, and otherwise – in IT-mediated surveillance systems designed to track “the” disease on a global scale. Investment in such surveillance has the effect of marginalizing key actors in the epidemic, especially when this investment comes at the expense of local, grass-roots public health capacity.

To see how such marginalization might function, I follow the material of information beyond its databases, tracing it back to public health clinics, back to patients, and back to public health laboratories. These material dimensions complicate the abstractions made by large-scale, IT-mediated surveillance.

**Ontological and Epistemological Assumptions**

My exploration of public health surveillance is informed by the ontological assumption that surveillance is never merely about the representation of reality, but is always also implicated in the constitution of reality. This position runs counter to one that would posit a strict distinction between an objective reality and subjective interpretations of reality. It is a form of constructivism, but not a *social constructivism* in which causal power is attributed to abstract social forces. Nor is this position a hermeneutic constructivism in which language determines reality. Rather, it is a constructivism influenced by what Luciana Parisi describes as *abstract materialism* (2004: 28). In this ontological framework, which emerges from the materialism of philosophers like Benedict de Spinoza, Henri Bergson and Gilles Deleuze, reality is an evolving process, a constructing process, and not something that is entirely given in advance. Surveillance is part of this reality and contributes to its construction. The surveillance of disease exemplifies this process perfectly. It shapes the evolution of disease
by directing resources towards some problems and not others. Surveillance contributes to the ontology of disease.

Moreover, the ontology subtending this dissertation prohibits an easy acceptance of binary oppositions (between the material and the immaterial, or the epidemic and the endemic, or… the list goes on). It thus encourages a critique of the mainstream view that the body is material while its information is immaterial. In the context of public health surveillance, if information’s materiality is theorized, the material effects of IT are underscored. Consequently, IT cannot be understood as a mere tool that simply compiles a more accurate representation of communicable disease. Rather, IT-mediated surveillance shapes communicable disease; it structures “epidemic space,” the threshold occupied by “the continuous iteration between the microphysics of infection and the macrophysics of epidemics” (Van Loon 2005: 40). IT-mediated surveillance attempts to define the intensity of disease, the level of its normalization or pathologization. Whereas surveillance attempts to clarify the boundaries of disease, the ontological position taken in this dissertation is that the thresholds between these boundaries are as important as the bounded disease itself.

The ontological assumptions just discussed present some difficulties for epistemology, especially an epistemology that is founded upon a correspondence theory of truth. This epistemology is organized around a rigid, simplistic distinction between an objective reality and a knowing subject. It has its roots in the Cartesian distinction between mind and body, and in the Kantian solution to this distinction, posited in terms of *noumena* – the objects of understanding - and *phenomena*, or objects as they are understood (Kant 1787/2003: 257-275). In an epistemology where truth is determined by a correspondence between ontological reality and epistemological ‘facts’ that describe, to a greater or lesser degree, that said reality, there persists a rigid distinction between knowledge and reality.
What does it mean, however, to hold knowledge apart from reality? As Bruno Latour argues, this orientation towards knowledge must presuppose the possibility of a magic leap from reality to knowledge. The difficulty, Latour writes, arose when philosophers “started from a gap between words and the world, and then tried to construct a tiny footbridge over this chasm through a risky correspondence between what were understood as totally different ontological domains – language and nature” (Latour 1999: 24). Latour’s solution to this problem is to argue that “there is neither correspondence, nor gaps, nor even two distinct ontological domains, but an entirely different phenomenon: circulating reference” (ibid. 24). Latour describes the circulating reference as a “way of keeping something constant through a series of transformations” (ibid. 58). The circulating reference is the chain of transformations that take place as form and matter evolve in relation to each other (69-70). I find Latour’s characterization of the relationship between the ontological and the epistemological compelling. The only point I take issue with is his assertion that an “essential property of this chain [the circulating reference] is that it must remain reversible” (ibid. 69). This qualification allows Latour to secure meaning.

I diverge from Latour on this point and, while conceding that there may be an element of reversibility in the circling reference, assert that the chain itself has a duration, and so there must also be an element of irreversibility (Prigogine and Stengers 1984). This divergence notwithstanding, Latour marks out a worthy path, a path I aim to follow and extend, by problematizing the over-simplified realism of epistemologies that are founded upon a correspondence theory of truth. This over-simplified realism imbibes conceptions that hold information to be immaterial. Accordingly, such over-simplified realism is a corollary target of the critique undertaken herein.
Moreover, the ontological and epistemological assumptions that underpin my investigation of public health surveillance prompt an evaluation, not just of large-scale IT-mediated surveillance, but also of the concept of public health surveillance itself. Instead of taking this concept for granted, as an over-simplified realist approach would, I inquire into the vast range of actors and practices that perform public health surveillance. This sets my dissertation apart from instrumental evaluations of health surveillance, the purpose of which is commonly “to promote the best use of public health resources by ensuring that only important problems are under surveillance and that surveillance systems operate efficiently” (Klaucke 1992: 26). For Douglas Klaucke, “…the strength of an evaluation depends on the ability of the evaluator to assess these characteristics with respect to the system’s objectives (ibid. 26). In this dissertation I probe beyond a given surveillance system’s stated objectives.

My analysis complicates the managerial approach to surveillance by locating surveillance practice in a broader assemblage of actors. Like other evaluations of surveillance, mine is concerned with issues of efficiency, costs and benefits. But these are not my only concerns. By locating the concept of public health surveillance in historical context, and by empirically exploring its attendant practices, especially as they have been shaped by IT systems and distributed decision-making processes, I aim to enroll a wide range of concerns in the evaluation, not just of efficiency, but also of the broader purposes of public health surveillance.

Methodology

In order to elicit perspectives not normally considered in instrumental evaluations I have adopted an exploratory approach, relying primarily on conversations with participants in public health surveillance. This approach leads into a “sociology of associations” (Latour:
2005: 5), thereby shedding light on the wider chain of relations involved in the performance of public health surveillance. The benefit of this approach is two-fold. First, by concentrating on the associations involved in the performance of public health surveillance, the “surveillant assemblage” (Haggerty and Ericson 2000) is “distorted into clarity” (Law 2004: 2). In other words, the assemblage of different actors involved in surveillance – be they human, machine, or otherwise – becomes clearer. Second, recognizing different practices that constitute this assemblage, it becomes apparent that public health surveillance is “[m]ore than singular” (Mol 2002/2005: 5). Indeed, public health surveillance is multiple, and this calls for an exploration of the many processes that allow it to “hang together somehow” (ibid. 5).

To undertake this exploration, I draw from a series of semi-structured, open-ended interviews with key informants (Dexter 1970; Kvale 1996; McCracken 1988; Merton and Kendall 1946; and Rubin and Rubin 2005). This approach differs from previous empirical studies of surveillance that have relied on ethnographic methods. A key reason for choosing interviews over ethnography is that there are numerous public health units in Ontario, and each health unit is responsible for providing public health services, including surveillance. Consequently, an ethnographic approach, focused on one or two organizations, would give too narrow a view of the range of different frontline surveillance practices in the province. For this reason, I decided that interviews with people from different health unit areas, or catchment areas, would allow me to cast the scope of my analysis more broadly, and get a richer picture of the heterogeneity of surveillance practices in the province.
The Setting

Ontario is Canada’s second largest province, covering over a million square kilometers. It is also Canada’s most populous province, with over 12 million inhabitants. The size and diversity of Ontario’s population and geography, relative to the rest of Canada, make it an interesting empirical site for the present study. For instance, its large population makes Ontario one of the four data exemplars for estimating the state of HIV/AIDS incidence and prevalence in Canada (Canada, PHAC 2006: 2). Additionally, the size and geography of Ontario pose challenges for the unification of surveillance systems. Some public health units are responsible for compact areas while others are responsible for vast territories. For instance, while Toronto Public Health serves a population in excess of 2.6 million, its territory spans just 630 square kilometers. In contrast, the northern catchment areas are much more sparsely populated, and the largest, served by the Thunder Bay District Health Unit, spans over 250,000 square kilometers. While southern health units, such as Kingston, Frontenac, and Lennox & Addington Public Health, can maintain a centralized office, northern health units must have several branches. For instance, The Northwestern Health Unit requires 14 different offices to service its 166,514 square kilometer territory. These different structural features pose significant challenges for health information systems and surveillance.

Additionally, with respect to government investment in IT, Ontario stands out as a key experiment. The 2005 implementation of iPHIS provided an opportunity to assess the difficulties involved in creating a large-scale public health surveillance system. The lessons learned from the iPHIS process are especially poignant as Ontario moves ahead to replace iPHIS with Panorama. The province is well positioned to learn from the experience of public health workers, whose labour was not adequately accounted for within iPHIS.
The Interviews

In Canada, following the SARS outbreak, there was a broad consensus that more needed to be done to create a regionally compatible, nation-wide communicable-disease surveillance system (see, for instance: Canada, NAC 2003; Ontario EPS 2003 and 2004; Ontario, SARS Commission 2004 and 2006). Approaching this discourse from a surveillance studies perspective, I was struck by the absence of critical perspectives; surveillance, it seemed, was framed in this discourse as though it were an unmitigated public good. I supposed that the broad consensus was achieved, in part, because counter-arguments about public health surveillance had been put into abeyance during and shortly after the SARS crisis. Moreover, I assumed that such differences of opinion might be identified by interviewing people in different areas of the province and with different structural relations to surveillance. To this end, I set out to interview doctors, patients, nurses, epidemiologists, government workers, and laboratory workers.6

In broad terms, my goal was to find out how people oriented themselves towards surveillance in public health. More specifically, I was interested in learning, from the perspectives of my research participants, what surveillance in a public health setting was all about.7 I wanted to find out by what steps people’s personal health information became a surveillance product. I was also interested in finding out about what technologies were used for surveillance. Additionally, as mentioned, I wanted to see if different understandings of surveillance, as well as different understandings of core concepts like health, illness, and disease, might create tensions when brought together under the rubric of an integrated surveillance system. Between December 2005 and January 2008, I conducted 64 interviews. A list of interviews is presented in the Appendix.
In order to find out about surveillance practices in public health, I interviewed people from 19 different public health units across the province of Ontario. Between December 2005 and September 2007, a total of 38 semi-structured, open-ended interviews were conducted with Medical Officers of Health, Associate Medical Officers of Health, Epidemiologists, Managerial Staff, and Public Health Nurses. Interviews were conducted by phone and lasted an average of 30 minutes. To recruit participants, letters of information were sent to 33 health units in Ontario. Further participants were then recruited using a snowball sample technique.

To get a sense of how patients experience surveillance in a public health setting, I decided to interview people who have had the experience of being screened for HIV. This focus, of course, is in no way representative of the patient experience of screening, if there is such a thing. Additionally, as public health discourse tends to distinguish between testing, screening and surveillance, it could be argued that patients do not experience surveillance per se, since surveillance has to do mainly with aggregated, anonymized information. Nonetheless, a portion of surveillance data comes from the testing of individual patients, and the screening of sub-populations. For this reason, I treat the testing and screening experience as part of the surveillance process.

Moreover, I settled on HIV/AIDS surveillance because of its dynamic history (Berkelman et. al. 1992). While the scope of my analysis precludes a comparison of surveillance experiences across different kinds of disease, it does indicate how disease screening-surveillance changes over time. To gather the perspectives of those who have had an experience with HIV-screening, I interviewed participants at a 2005 Opening Doors conference. Additional participants were recruited through a community-based HIV/AIDS organization. I was interested to find that, for the patients I interviewed,
surveillance had little cognitive resonance. As I will discuss, my interviews indicated that, although most people had a good deal of trust that their personal health information would be handled in a confidential manner, they had little to no knowledge of exactly where their health information was, or how it might be used for surveillance.

Part of the reason why people have little understanding of what happens to their personal information when they are tested for HIV has to do with the highly technical nature of the testing, screening and surveillance process. I will explore this process by drawing from interviews with patients and public health professionals. I also rely, for this exploration, on a set of interviews, conducted between August 2006 and January 2008, with infectious disease specialists, laboratory scientists, and laboratory technologists. These interviews help me to explain the HIV testing-screening-surveillance process.

In sum, the interviews I conducted enable an exploration of some of the countless different practices, performances, and relationships that make up surveillance in a public health setting. I made transcripts for 50 of the 64 interviews I conducted. These were then returned to the interviewee for revision or comment. Once revisions were made, I then thematically coded and analyzed the transcripts. I concluded most interviews by asking participants to comment on what they felt was working well, with regards to public health, and what they wanted to see change (please see interview guides in Appendix). Hence, these interviews helped me to identify different configurations and possibilities for surveillance in a public health setting. I think these different possibilities are, unfortunately, being erased by the instrumental pursuit of large-scale, IT-mediated surveillance. The complex different ways of doing surveillance are being standardized and flattened out by the attempt to build province-wide, nation-wide, and even world-wide surveillance systems. Although such transformations promise certain gains, they also engender significant losses.
Although computer-mediated public health surveillance is a relatively new phenomenon, the desire to achieve globally standard “disease concepts” is not (Duffin 2005). The archetypal expression of this desire has been the International Classification of Disease (ICD), now on its tenth revision (Bowker and Star 1999; WHO 2008a). While such classification projects have always worked to smooth out local differences, the crisis-driven attempt to make these projects ever more comprehensive could actually be detrimental to public health. Some of the reasons for this emerge from my interview data.

Limitations

The research conducted for this dissertation is exploratory in nature. Consequently, the results are not generalizable in any strict sense. Additionally, research participants were actively sought, rather than randomly selected, and the study consequently has a selection bias. Also, I eschewed a systematic collection of some demographic data, for instance how long a person had worked in public health, or how many different health units they had worked at. I did so because I wanted to spend my time talking with participants about their perspectives. The study was not, therefore, designed to weight participants’ responses according to experience, or to cross-validate responses. By producing transcripts of interviews, my goal was not to capture some supposed ‘truth of the moment’. Rather, my goal was to produce working documents that could guide an on-going dialogue.

Although these limitations constrain the degree to which the findings of this dissertation may be generalized, the dialogic approach that I have adopted permits a degree of reflexivity that is, I believe, crucial for a study of surveillance practice. Indeed, what does it mean to undertake what is in effect the surveillance of surveillance? There is a sense in which the surveillance of surveillance is paradoxical.\textsuperscript{12} Basically, the surveillance of
surveillance adds to surveillance, changing the nature of surveillance. As an observer of public health surveillance, I inscribe the practices I relate here with meanings that they did not have before I wrote about them. This is not to say that these practices had no meaning before my observation of them; rather, it is to say that my writing participates in the duration of these practices, adding a further (real) frame to their existence. This situation necessitates a degree of reflexivity on the part of observers in order to account for, if not limit, their fundamentally constitutive role in observation. If surveillance amounts to taking a snapshot of a dynamic situation, the surveillance of surveillance must, if it is to be reflexive about its paradoxical foundation, work towards a motion-picture perspective.

The title of this dissertation, *Picturing Public Health Surveillance*, signifies the activity of taking different points of view with relation to surveillance. In a sense, the empirical chapters may be viewed as frames on a reel, with each frame containing a subtly different picture. By concentrating on different aspects of the materiality of public health surveillance I have presented a series of pictures which, while not generalizable to public health surveillance *writ large*, suggest a fundamental relationship between the way surveillance is configured and the way disease is perceived. Different configurations of surveillance produce subtly different epidemiologies, each with their own politics.

**Chapter Summary**

The immaterial conception of information is, I contend, constraining the contemporary development of public health surveillance. As I will argue in chapter 2, the idea that information is *immaterial* is implicitly assumed in discourse that promotes investment in IT as a solution to problems faced by the medical care and public health systems. This assumption presupposes that IT-instantiated information can stand outside of space and
time. It thus presupposes that IT-instantiated information can remain changeless regardless of the material context in which it is iterated.

This dissertation explores two major consequences that flow from the material pursuit of immaterial information. The first major consequence of this pursuit is an investment in health IT at the expense of other health priorities. The second major consequence of this pursuit is a systemic marginalization of the material assemblages that instantiate information. Taken together, these consequences paradoxically drive immaterial conceptions of information to a position of dominance in discourse on public health surveillance. They contribute to a “powerful and profound faith in the myth that technology can accelerate positive social change, and an equally profound historical amnesia with regard to promises made about earlier technologies” (Mosco 2004: 139-140 –note omitted).

Discourse on public health surveillance is furnished with several examples of the dominant position ascribed to the myth of immaterial information. The following case in point briefly illustrates the kinds of issues at stake in the material pursuit of immaterial information. *Principles and Practice of Public Health Surveillance*, a widely used textbook first published in 1994, contains a chapter entitled “Computerizing Public Health Surveillance Systems”. At the outset of this chapter, the contributing authors depict a utopic vision for twenty-first century epidemiology and laud the apparent capacity of information technology to thin the “herd of clerks” (Dean et al. 1994: 206) that make surveillance possible. A future generation of epidemiologists, the authors opine, will be able to send a fax-like request to households, instructing them to “tune to a particular channel and answer a 5-minute query from the state health department on a matter of importance to public health” (ibid. 201). “Eighty-five percent of the subjects respond to the first query,” they continue, “and the
computer automatically follows up with the rest, bringing the response to 92%, with half of
the remainder reported to be absent from their homes for at least 2 days” (ibid. 201).

This scenario is at once reassuring and chilling. Perhaps it is disingenuous to assail
the authors for failing to consider privacy concerns. Perhaps the issue of poverty, ignored in
the assumption that all homes have a television, and that everyone has a home, lies beyond
the scope of this scenario. After all, the authors were merely attempting to illustrate the
benefits of moving towards computer-mediated public health surveillance systems.
Nevertheless, these are the precise kinds of concerns that fade to the margins when the
immaterial conception of information pervades. These are the kinds of concerns that are
immaterialized by the immaterial conception of information. In other words, these concerns
are made immaterial, not in the sense of being stripped of their materiality, but in the sense
of being rendered unimportant. In this dissertation, I explore how the immaterial
conception of information can have such an immaterializing effect.

To stage this exploration, I review literature that propounds an immaterial
conception of information in chapter 2. I link the rise of this conception to the
intensification of surveillance, and I review literature from the emergent, interdisciplinary
field of surveillance studies in order to position my research. To preview that review, within
surveillance studies scant attention has been paid to surveillance in a public health context,
and still less attention has been paid to public health surveillance practice. This dissertation,
therefore, begins the work of filling that gap in surveillance studies.

In chapter 3, I suggest that the immaterial conception of information, in a public
health setting, is related to an ideational and institutional history in which information was
meant to be controlled by authorities on a ‘need to know’ basis.13 These historical
conditions are reflected in contemporary definitions of public health surveillance, and in the
conceptual de-linking of screening from surveillance in public health discourse. A legacy of these historic institutional and ideational configurations is the subordination of local orders of concern.\textsuperscript{14}

In chapter 4, I concentrate on the implementation of iPHIS, as well as the problems that accompanied its introduction. On the one hand, this exploration reveals the complexity and heterogeneity of local health surveillance practice. On the other hand, it shows why large-scale information systems must subordinate these local orders of concern in order to function, and how the materiality of these concerns complicates such large-scale projects.

Chapter 5 repositions the scope of analysis. That is, I move from considering communicable-disease surveillance, to considering the surveillance of one communicable disease: HIV/AIDS. At the same time that this focal point is narrowed, I begin to broaden the analytic scope by concentrating on some of the extra-corporeal spaces of negotiation in which blood is translated into information.

In chapter 6, my focus turns to HIV “itself”. This chapter suggests that the network that actualizes HIV misses the material liveliness of the virus. I discuss the paradoxical way in which surveillance processes both concretize and unsettle identities. As presently configured, the current screening and surveillance regime privileges the form of viral identity over the matter of the virus. This process exemplifies yet another way in which material heterogeneity is flattened out by the immaterial conception of information.

Chapter 7 concludes the dissertation by arguing that there is a need to re-conceptualize what is meant by public health surveillance. Attending to the materiality of information brings local orders of concern back into the picture: the labour of information processing comes to the fore; patients’ bodies and experiences come to the fore; and, the heterogeneity of communicable disease comes to the fore.
Chapter 2: Literature Review

In 1996, amidst the euphoria generated by the apparent success of the so-called information revolution, a group of conservative American intellectuals provocatively proclaimed that the central event of the 20th century had been “the overthrow of matter” (Dyson et al., 2004: 31). Today, information is widely assumed to be immaterial, especially when it is instantiated in IT. This assumption endows information with extraordinary power, not the least of which is the power to conquer space and time. Immaterial information, it is supposed, can be in many places at once; it takes on a timeless, even transcendental quality. In this chapter I argue that IT’s promise to immaterialize information is both a key resource, and principle reason, for the intensification of large-scale, IT-mediated surveillance.

The apparent capacity of immaterial information to transcend space and time makes it a key resource for surveillance. I say apparent capacity because it is worth recalling that information was not always supposed to be immaterial. As N. Katherine Hayles observes, information seemed to lose its body as a particular technical definition of information came to be ascendant within the cybernetics movement. Although this definition was initially vigorously contested, by Donald MacKay (1969) among others, this contestation has subsequently faded into the backdrop. As the cybernetics movement plugged into larger economic, political, social and scientific transformations, such as the shift from Fordist to post-Fordist modes of production or the growing convergence between computer science and molecular biology, it became more common for people to contend that “the universe” was “composed essentially of information” (Hayles 1999: 11). This created a paradox whereby at the same time that information was becoming immaterialized, the material universe was becoming informationized.
I contend that this paradox is a foundational reason for the intensification of large-scale, IT-mediated surveillance. On the one hand, IT-mediated surveillance promised unprecedented levels of control. On the other hand, this promised control required the creation of conditions that opened up new vistas of uncertainty. To begin with, if material elements could be assigned an immaterial and easily controllable counterpart in the form of information, then IT-mediated surveillance could promise an unprecedented level of control. This promise was made under the rubric of the immaterial conception of information and premised upon the idea that IT could actually immaterialize information, could actually render information static, eminently readable, and endlessly translatable regardless of contextual specificities. However, if all material elements could be treated as information and thus made endlessly translatable, then complexity increased exponentially and IT-mediated surveillance had a lot to try to control, a lot to try to immaterialize.

In this sense, the immaterial conception of information is both a key resource for, and cause of, the intensification of surveillance. It engenders the globalization of surveillance. This is expressed in the propensity to try to capture an ever-more global, ever-more universal, ever-more objective and transcendental perspective. In public health and medical care contexts, the immaterial conception of information participates in the modern drive to render bodies (and bodies politic) visible. As Catherine Waldby argues, “new perspectives opened on to the bodily interior by […] technoscientific] modes of vision suggest that the body at the end of the second millennium is utterly available as visible matter” (2000: 2). These modes of vision are extended, via the immaterial conception of information, to both microscopic and macroscopic scales of complexity.

Focusing on public health surveillance, I explore some of the counter-intuitive consequences that accompany the widespread investment in the immaterial conception of
information. To stage this exploration, I take a page from Hayles (1999) and track the discursive movements that divested information of its body. In the first section of this chapter I review literature from cybernetics, social scientific and health policy discourse in order to show that, as the conception of immaterial information emanated beyond the borders of cybernetics country, it shed debate over its veracity, especially with regards to IT.

In both social scientific and health policy contexts, the immaterial conception of information propels writers to accord IT an extraordinary power. When IT is accorded such power, IT-mediated surveillance appears especially valuable. And yet, even as it promises to solve pressing problems, IT-mediated surveillance can also create problems. Literature from the field of surveillance studies has assessed such surveillance-created problems. A core concern of this field has been the proliferation of IT in the name of achieving increasingly fine-grained “dataveillance” (Davis, cited in: Genosko and Thompson 2006: 125; see also: Clarke 1994; 1999; 2000). I review literature from surveillance studies in the second part of this chapter and argue that this field contains some excellent resources for exploring the material dimensions of information in public health surveillance systems. At the same time, however, surveillance studies remains underdeveloped in some key areas. For instance, there is a dearth of empirical work on surveillance in medical care and public health contexts. While this is beginning to change, as evidenced by Monahan and Wall (2007) among others, a significant amount of work remains to be done. This dissertation, therefore, contributes to this effort by reviewing what literature already exists, and by contributing empirical analysis to an understudied area.
The Rise of the Immaterial Conception of Information

In this section I briefly review literature from three different domains in order to flesh out the philosophical underpinnings of the immaterial conception of information. I begin with a discussion of what became the dominant conception of information in cybernetics. I next draw comparisons between this cybernetic articulation of information and the articulation of information in a social scientific context. This comparison allows me to make some observations about the philosophical assumptions that endow information with immateriality, with the power to transcend time and space. Next I move to a consideration of texts that, while not explicitly engaged in the philosophy of information, implicitly assume an immaterial conception of information. These texts, which come from Canadian health policy literature, implicitly accept the paradoxical baggage associated with the immaterial conception of information. Consequently, they uncritically endorse the movement towards large-scale, IT-mediated surveillance.

Cybernetics and the Rise of the Immaterial Conception of Information

When, in 1948, Claude Shannon first published his now classic essay, “The Mathematical Theory of Communication,” his goal was to extend the general theory of communication, which had been nascent as early as the mid-1920s, to encompass a specific technical problem and its solution. These, Shannon described as the problem of “noise in the channel, and the savings possible due to the statistical structure of the original message and due to the nature of the final destination of the information” (Shannon 1948/1959: 3). For Shannon, the fundamental problem to be solved was “that of reproducing at one point either exactly or approximately a message selected at another point” (ibid. 3). To resolve this problem, he proposed to separate messages from their meaning. He writes: “Frequently […] messages
have *meaning*, that is they refer to or are correlated according to some system with certain physical or conceptual entities. These semantic aspects of communication are irrelevant to the engineering problem” (ibid. 3). From this statement, it is clear that, in order to work out a solution to “noise in the channel,” Shannon required a very circumscribed model of a communication system, as well as a specific and peculiar understanding of information.

As Warren Weaver put it, “*information*, in this theory, is used in a special sense that must not be confused with its ordinary usage. In particular, *information*, must not be confused with meaning” (Weaver 1959: 99). For Shannon, and for others who elaborated his theory, information had to be defined as a probability function. In other words, information referred “not to a single message, but probabilistically to an entire ensemble of possible messages” (Young 1987: 7). After it was published, Shannon’s theory radiated outwards, most notably through the interdisciplinary field of cybernetics.

In the same year that Claude Shannon published “The Mathematical Theory of Information,” Norbert Wiener published his *Cybernetics* manuscript. In this book, Wiener argues that the problems involved in understanding machinic and neurophysiological systems are essentially similar. They centre, he contends, on the “fundamental notion of the message, whether this should be transmitted by electrical, mechanical, or nervous means” (1948: 16). Like Shannon, Wiener was concerned to theorize communication in relation to noise. “We often find a message,” Wiener writes, “contaminated by extraneous disturbances which we call *background noise*. We then face the problem of restoring the original message…” (ibid. 17). To solve this problem of getting back to the original, Wiener, who had been in conversation with Shannon, proposed a similarly esoteric definition of information. In a chapter entitled “Computing Machines and the Nervous System,” Wiener argues: “The mechanical brain does not secrete thought ‘as the liver does bile’, as the earlier
materialists claimed, nor does it put it out in the form of energy, as the muscle puts out its activity. *Information is information, not matter or energy*” (ibid. 155 –emphasis mine). Hence, like Shannon, though in more explicit terms, Wiener sets information apart from matter.

What distinguishes Wiener’s text from Shannon’s is his discussion of the philosophical foundations for the immaterial conception of information. “If I were to choose a patron saint for cybernetics out of the history of science,” Wiener writes, “I should have to choose Leibniz” (ibid. 20). Wiener lauds Leibniz, not so much for his monadology, which placed each monad “in its own closed universe” (ibid. 52), as for his universal symbolism and calculus of reasoning (ibid. 20). Indeed, although Wiener found Leibniz’s monadology wanting, believing himself that the monads “of the present age are coupled to the outside world both for the reception of impressions and for the performance of actions” (ibid. 55), the definition of information given in *Cybernetics* is remarkably like that which Leibniz gave to the monad. In *Cybernetics*, information, by virtue of its separation from matter, is in its own closed universe.

*Immaterial Information in a Social Scientific Context*

As Hayles (1999) argues, the immaterial conception of information has traveled far beyond the borders of cybernetic country. Occasionally, information is explicitly defined as immaterial, as in Wiener’s *Cybernetics*. More often, however, information is implicitly, or at least ambivalently, conceived of as immaterial. Statements about information’s timelessness or spacelessness convey this implicit assumption. In order to illustrate the operation of the immaterial conception of information in a social science context, I turn now to the work of Manuel Castells.
In his monumental three-volume study, entitled *The Information Age*, Castells offers an encyclopedic account of information in contemporary society (Webster 2002: 97). I will focus on the first volume of Castells’ study, *The Rise of the Network Society*, as it is in this text that he advances the notion of *timeless time*. Although Castells has a largely materialist view of information, his conception of timeless time suggests a slippage from materialism. Before making this argument, let me first situate the concept of timeless time in relation to Castells’ larger project. Following Daniel Bell (1976), Castells argues that the industrial mode of development has been surpassed by a new, informational mode of development. The source of productivity in this new mode of development lies not in harnessing new kinds of energy, but “in the technology of knowledge generation, information processing, and symbol communication” (1996/2000: 17). Castells’ definition of information is drawn from Marc Porat’s (1977: 2) *The Information Economy*: “[i]nformation is data that have been organized and communicated” (Castells 1996/2000: 17). For Castells, the emergence of the information age marks a revolutionary transition.

“What characterizes the current technological revolution is not the centrality of knowledge and information,” Castells writes, “but the application of such knowledge and information to knowledge generation and information processing/communication devices, in a cumulative feedback loop between innovation and the uses of innovation” (ibid. 31 – note omitted). This situation prompts Castells to contend that, “[f]or the first time in history, the human mind is a direct productive force, not just a decisive element of the production system. Thus, computers, communication systems, and genetic decoding and programming are all amplifiers and extensions of the human mind” (ibid. 31). Here is the first glimpse that information might, in this work, be something other than material. It is the
mind, as something distinct from the body, from the embodied nervous system, that is the
driving force of this new productivity.

There remains, however, an ambivalence in Castells’ position. Information is not
explicitly immaterial, as was the case in Wiener’s definition. Rather, information is
paradoxically im/material. For instance, the information revolution is nested in the
developments of the industrial revolution. The industrial revolution “extended and
augmented the power of the human body, creating the material basis for the historical
continuation of a similar movement toward the expansion of the human mind” (ibid. 38 –
emphasis mine). Moreover, information is likened to the “raw material” (ibid. 70) of the
new age. Given these assertions, the critical question becomes how to determine where and
when information is viewed, by Castells, as immaterial.

I will now suggest that this occurs when Castells sets information apart from its
spatial and temporal context. Castells, like Wiener, assumes that information can be set
apart from its material context. However, unlike Wiener, Castells does not assume this
immaterial definition of information in an a priori manner. Rather, for Castells, information
is immaterialized when it is instantiated in networked IT. On the one hand, he accords to IT
an extraordinary, deterministic power, granting it a universe-making capacity. On the other
hand, IT-mediated communication remains socially situated: “it reinforces pre-existing social
patterns” (ibid. 393). In this way, parameters are placed around the immaterial conception
of information. Nonetheless, this conception retains a prominent place in Castells’ analysis.

Taking a page from Marshall McLuhan (1964/1967), Castells argues that IT enables
“the integration of various modes of communication into an interactive network. Or, in
other words, the formation of a hypertext and meta-language which, for the first time in
history, integrate into the same system the written, oral, and audiovisual modalities of human
communication” (ibid. 356). The empirical examples used to substantiate this claim about a new, global meta-language say little about the information-processing practices that make it up. By pushing the minutiae of these practices to the analytic margin, it becomes possible for Castells to theorize a “digital universe that links up in a giant, non-historical hypertext, past, present, and future manifestations of the communicative mind” (ibid. 403). This is a universe that is characterized by timeless time, an atemporal temporality that Castells surprisingly draws out of Leibniz. He proposes that “the Leibnizian notion of time” (ibid. 494) can help readers to understand the ongoing transformation of temporality.

For Leibniz, Castells argues, “time is the order of succession of ‘things’” (ibid. 494). Timeless time, then, “occurs when the characteristics of a given context, namely, the informational paradigm and the network society, induce systemic perturbation in the sequential order of phenomena performed in that context” (ibid. 494). The problem is that Castells equates the perturbation of the sequential order of time with the creation of undifferentiated time. In so doing, I think Castells accords far too much efficacy and power to IT. Certainly IT has the capacity to condition the experience of space and time. It is even possible to suggest, as Castells does, that because space and time are human concepts, and because humans are social, space and time are themselves fundamentally transformed by their interaction within the socio-technically produced IT universe. However, even conceding this debatable point, Castells still goes too far in suggesting that IT creates a timeless time. It is one thing to argue that the experience of time is compressed by IT; it is quite another thing to suggest that compressed time is timeless time.

Let me pause to sum up the argument thus far. In Wiener’s *Cybernetics* information is conceptualized as immaterial; it is set apart from matter and energy. Although Wiener rejects Leibniz’s monadology, he theorizes information as though it were a kind of monad,
as though it were in its own universe. Similarly, Castells grants information, instantiated in networked IT, the property of timeless time. This, I think, is tantamount to granting information an exemption from the material universe; it puts information in its own universe thus making it a kind of monad. Additionally, the fact that both authors appeal to Leibniz is not, I think, insignificant. Gilles Deleuze argues that, for Leibniz, the monad “is the autonomy of the inside, an inside without an outside (1988/1993: 28). Both Wiener and Castells make information a monad in this sense. Both place too much emphasis on the distinction between information and everything else. Without wanting to digress further into an excursus on this subject, it will suffice to suggest here that, where they make a monad of information, both authors relegate the material dimensions information to a level of second-order import.

With this suggestion in view, I now want to explore discourse that is not concentrated on theorizing information, but which takes an immaterial conception of information, complete with its paradoxical baggage, for granted.

Immaterial Information in Policy Contexts

During the waning years of the twentieth century, as Canadian governments enacted a series of neo-liberal reforms designed to roll-back the institutional mechanisms of the welfare state, it became commonplace to conceive of the Canadian medical care system as though it were in a permanent crisis (Armstrong et. al., 2001: 1-6). This apparent crisis, characterized by a situation of scarce resources, prompted a fundamental re-thinking of medical care delivery in every province, as well as federally. As Chandrakant Shah observes, each province, and the federal government “appointed various task forces, commissions, boards of inquiry, and working groups to conduct their own fundamental reviews…” (2003: 531). One of the
major themes in this review process was the development of health IT, especially electronic health records. IT was widely regarded as a, if not the, key means of getting spending on medical care under control.

In 2002, two major federal-level reports – the Romanow Report and the Kirby Report – were released. While Romanow and Kirby disagreed on how best to fix the medical care system, neither doubted that IT would be a prominent part of any way forward. Just a year later, the Canadian health system faced a different kind of crisis, this one heralded by the threat of twenty-first century disease. Reviewing what went wrong during the SARS outbreak, the 2003 Naylor Report – another federal-level report – cited the public health system’s lack of IT, among other things, as a problem. While these reports were written in response to different crises, and while they posited a plethora of different solutions, all placed a steadfast faith in IT. This owes largely, I think, to the questionable assumption that IT-mediated information is immaterial. Such assumptions have the effect of eliding the amount of work involved in translating information from one context to another. Below I will focus first on the Romanow Report, then on the Kirby Report, and finally on the Naylor Report.

A key issue in the Romanow Report (and in the Kirby Report) was whether the publicly-funded, universal-access medical care system could be sustained, and what degree of private enterprise was acceptable. Arguing that “Canadians view medicare as a moral enterprise, not a business venture” (Canada, Romanow 2002: xx), the Romanow Report advocated for the continuation of the publicly funded system. However, Romanow also argued that some things had to change. One reform measure considered by Romanow was the public-private partnership (otherwise known as P3s). These were received coolly by Romanow, but not rejected out-right. The report stated that P3s were not without a place in
the Canadian medical care system, “for example in the case of health information systems” (ibid. 30). Though Romanow cautioned that the value of P3s needed to be carefully considered, he left the door open to them where “ancillary services” (ibid. 6) were concerned.

If the electronic processing of health information could be considered an ancillary service, not as directly related to medical care delivery as, say, surgery, the place of IT itself was anything but ancillary. Romanow argued that, by putting the necessary information infrastructure in place, by improving the management and assessment of medical care technology, and by expanding capacity for applied research, “the health of Canadians” (ibid. 76) could be improved. A central part of this three-pronged approach to improving the health of Canadians was the Electronic Health Record (EHR). According to Romanow, the EHR could address some of the problems posed by the existing record system, “an assortment of non-standardized patient information stored in isolated patient records” (ibid. 77). In his view paper records were “increasingly becoming obsolete and inadequate” (ibid. 77). After a rehearsal of the limitations of the paper-based record system, Romanow described the potential advantages offered by the EHR. According to the Report, EHRs could improve diagnoses and treatments by giving medical care providers access to “complete personal health information” (ibid. 78), and by linking this information to clinical support tools. EHRs could improve the accuracy of personal health records by centralizing patient information. They could make medical care delivery more efficient by reducing the amount of time nurses spend managing paper records. They could improve the security of patient records, provided the necessary precautions were taken. They could improve access for individuals to their health information (ibid. 78). They could provide aggregate data for
policy makers, for health research, and health surveillance (ibid 78-79). Given the benefits enumerated, Romanow’s recommendation for greater investment in IT is unsurprising.

For Romanow, EHRs represented the foundation of other tertiary tracking mechanisms, such as cross-nationally standardized systems designed to measure performance indicators. The efficacy of vaccination programs could be tracked. Adverse reactions to pharmaceuticals could be monitored. Tertiary systems designed to monitor these effects should, in Romanow’s view, be linkable with each other and with the EHR (see, for instance: ibid. 208).

As Romanow envisioned it, the EHR created a win-win situation. It could increase the efficacy of medical care and, at the same time, empower patients. The capacity of information to overcome obstacles of space and time could enable individuals to have a level of medical knowledge, and a medical management capacity, heretofore unimagined. To illustrate this potential, Romanow offered a series of vignettes. These exemplify the implicit assumption that information is immaterial. For instance:

A 12-year-old boy has been diagnosed with juvenile diabetes. He needs to track his insulin levels and other information about how he is feeling through the day and provide that information to the health management team that is monitoring his care. With that information, they can regulate his dosage of insulin, his diet, his activity levels, and help manage his care. The boy uses a mobile device like a Palm pilot. He feeds information into the Palm pilot during the day, and at night, he hooks it up to his home computer, types in his personal identification number, and sends it to the health management team. During regular meetings, he and his parents go over the information with the health management team. He and his parents can also use his personal identification number to access information about juvenile diabetes, especially research that is underway to find a cure (ibid. 82).
Conspicuously absent in all of this discussion about the benefits of technology is a detailed consideration of the labour required to deploy such technology effectively.

In the Kirby Report, a similar silence is observed. Kirby differed from Romanow on the issue of privatization in the Canadian medical care system. He stated that, while “not pushing for the creation of private, for-profit, facilities […] they should not be prohibited…” (Canada, Kirby 2002: 54). While Romanow can be said to have left the door ajar for P3s, Kirby attempted to remove the door altogether.

But, like Romanow, Kirby locates the EHR at the foundation of a system-wide health information network. In Kirby’s view, the EHR could “make patient data available to health care providers and institutions anywhere on a need-to-know basis by connecting interoperable databases that have adopted the required data and technical standards” (ibid. 175 –emphasis mine). Note the phrasing that I have emphasized in this quotation. In the next chapter I will examine the idea that health IT can give health workers better control over information, endowing them with the capacity to easily distribute it on a need-to-know basis. The idea that information can be easily controlled and distributed is connected, fundamentally, to its conception as immaterial. For the present, let me illustrate how the Kirby Report implicitly assumes information to be immaterial.

Quoting a lengthy passage of a letter from the president and CEO of Canada Health Infoway (CHI), the Kirby Report states:

National, interoperable EHR solutions that bring comprehensive and portable information to health providers and their patients will empower Canadians and help to significantly improve the quality, safety, accessibility, timeliness and efficiency of services. Furthermore, EHR solutions will enable the creation, analysis and dissemination of the best possible evidence from across Canada and around the world as a basis for more informed decisions by patients, citizens and caregivers; by health
professionals and providers; and by health managers and policymakers. They will also help maximizing [sic] the return on ICT investments through alignment, and drive the development of common standards and interoperability (ibid. 176).

This vision was enthusiastically embraced by Kirby, who recommended that the federal government provide $2 billion to CHI for the purposes of developing a national EHR system (ibid. 177). As Kirby noted, such investment would likely transform “the traditional, bilateral relationship between patient and provider,” morphing it “into a more complex web of interactions between the patient and the health care system” (ibid. 179). This observation rests on a strong distinction between paper records and electronic records, and, in this respect, the Kirby Report and the Romanow Report are on the same page. Kirby argued:

By their very nature, paper records are limited to discrete pieces of personal information that could feasibly be gathered in paper form, contained in a specific physical location […] This contrasts with EHRs, which can assemble a more complete, comprehensive and longitudinal record of a person’s health information originating from multiple sources, captured in electronic form that is readily available and potentially accessible to multiple authorized users, in real-time, irrespective of location” (ibid. 179-180 –emphasis mine).

Certainly, electronic records are different from paper-based records; for instance, they can be distributed in ways that paper records cannot. However, it seems that electronic information, here, is immaterial. Note, the phrasing that I have emphasized. EHRs can assemble… In fact, EHRs cannot assemble information in the absence of labour, or for that matter, patients and their various ailments.
Kirby, like Romanow, attributes an extraordinary power to electronic information. In this respect, both Kirby and Romanow follow the same path taken by Castells. All assume that information, once ensconced in IT, can take on a timelessness in some autonomous, cyber-spatial flow. This is to assume, as I argued above, that information is immaterial. It is certainly fair to assert that EHRs change the nature of health information processing. However, to deny the materiality of information in electronic records is to misunderstand the nature of this transformation.

Kirby and Romanow focus on the benefits of health IT without focusing on the coordination and translation work, at the level of information-processing practices, that it takes to attain such benefits. Both reports black-box information-processing practice, minimizing the heterogeneity and complexity of these practices. In so doing, they elide three kinds of specificity. First, they elide the specificity of the labour involved in information-processing. Second, they elide the specificity of the patients whose information will be the ostensible object of this technological intervention. Third, they elide the specificity of challenges posed by different health determinants to the medical care system. These elisions stem from the assumption that information is immaterial. They play out against the backdrop of a perceived economic crisis.

In 2003, the SARS outbreak presented the medical care and public health systems with a crisis of a different kind. In contrast to the slow corrosion induced by economic cutbacks and neo-liberal reforms, the SARS crisis came as a staccato series of shocks. In the wake of the first wave of the outbreak, the Canadian federal government convened an expert panel, chaired by then University of Toronto Dean of Medicine, David Naylor, to look into what went wrong. The Naylor report identifies the public health system’s lack of networked IT infrastructure as a factor that contributed to the severity of the SARS outbreak. Whereas
the previous reports discussed the ways that IT could improve medical care delivery, this report argued that an absence of IT inhibited health protection efforts by making disease surveillance difficult.

To begin, the Naylor Report identifies a number of deficiencies in the public health system, one of which is related to IT. The Report states:

The lack of a modern database accessible to local, provincial, and federal health authorities had adverse impacts on the flow of information to the public and international agencies. The absence of appropriate and shared databases and capacity for interim analyses of data, also interfered with outbreak investigation and management, and constrained epidemiologic and clinical research into SARS (Canada, NAC 2003: 29).

Interviewed for the Report was University of Toronto epidemiologist Dr. Ian Johnson, who had been seconded to the Ontario Ministry of Health to establish a SARS surveillance system. Johnson was critical of the province’s existing disease tracking and outbreak management software. He described it as “an archaic DOS platform used in the late eighties that could not be adapted for SARS” (cited in: Canada, NAC, 29). Drawing from Johnson and others, the Naylor Report argues that better IT could have facilitated epidemiologic investigations, communication amongst physicians about the most successful clinical interventions and the best practices for infection control, as well as inter-agency communication about the state of the outbreak.

Looking back through the history of public health Naylor observes that epidemiologists were “pioneering users of health information in the eighteenth and nineteenth centuries” (ibid. 67). Today, however, “public health, like the personal health care system, has been unable to take full advantage of innovations in information and
communication technologies” (ibid. 67). Naylor, like Romanow and Kirby, argues that EHRs have “the potential to be a rich source of surveillance data in the future” (ibid.92). But in the present, the absence of IT contributed to confusion on the frontline during the SARS outbreak.

It is noteworthy that all three reports discussed look to IT and, implicitly, to immaterial information as a solution to a perceived crisis. As I will argue in the next chapter, the development of surveillance and the development of crises have gone hand-in-hand. For the present, however, let me simply underscore the point that IT appears to be a good solution to perceived crises because it has been accorded an extraordinary power, the power to make information immaterial, to master information across space and time. Whether or not information is explicitly or implicitly assumed to be immaterial, its exemption from duration renders it as such.

As the immaterial conception of information was absorbed by discourse beyond the borders of cybernetic country, it shed debate over its veracity. At the same time, IT has been increasingly endowed with a tremendous power. This makes the investment in IT appear as a logical response to crises. However, recall my argument at the outset: at the same time that information was becoming increasingly immaterialized, the material world was becoming increasingly informationized. This paradoxical foundation of the immaterial conception of information provokes its own crisis. Borrowing from Kirstie Ball and Frank Webster, this crisis may be characterized as a “compulsion to surveille,” a compulsion “endemic in the modern world, where order and control are the requisites of all else” (2003: 5). In short, the immaterial conception of information fosters a tendency towards the intensification of IT-mediated information collection and surveillance processes. I turn,
now, to a discussion of surveillance, as well as a review of literature from the emergent field of surveillance studies.

**The Intensification of Surveillance**

Surveillance is not a novel phenomenon. It has existed at least as long as people have and, insofar as the activity of surveillance can be described as the practice of watching over something, it can certainly be said to predate humans. Nonetheless, as a field of scholarly inquiry, surveillance studies is comparatively new. Canonical sociologists – like Marx, Weber, Durkheim, and Simmel – did not explicitly address their work to surveillance. However, as Lyon (1994) notes, they did touch on surveillance-related issues in their discussions of the workplace, the bureaucracy, the community, and the metropolis. These commentaries, and numerous others besides, illustrate that surveillance has been a long-standing sociological concern. Despite the longevity of this concern, surveillance did not have a distinct place in the sociological lexicon until the 1970s, following the publication of James Rule’s *Private Lives and Public Surveillance* (1973), and Michel Foucault’s *Surveiller et Punir* (1975) (Lyon 1994: 6).

The history of modern, institutionalized forms of surveillance is, at best, a non-linear, “discontinuous” narrative (Higgs 2004: viii). Some have traced its rise to bureaucratic and militaristic forms of administration (Dandeker 1990). Others to the growth of liberal individualism and privacy (Nock 1993; Flaherty 1972 and 1989). Others, following Foucault, have linked surveillance to the development of disciplinary regimes, be they shrouded by criminal justice systems (Cohen 1985) or the capitalist marketplace (Gandy 1993 and 1996). Still others have identified the connection between the growing use of computer-mediated
IT and surveillance (Lyon 1986; 1988; 2005; and Lyon and Zureik 1996). Indeed, contemporary surveillance has many roots; its history is more rhizomatic than arborescent.

Lyon (2007) has provided an overview of surveillance studies literature. Rather than duplicating that work, this review concentrates on some key themes in the literature that are germane to public health surveillance. By focusing on risk, privacy, and responsibilization, I argue that the field of surveillance studies raises key questions about the abstraction of information from its material context, but has yet to overcome its preoccupation with personal information. Consequently, while surveillance studies is helpful for theorizing the relationship between the rise of the immaterial conception of information and the intensification of computer-mediated public health surveillance, its focus upon the consequences of surveillance for persons needs to be broadened.

**Surveillance and Risk**

Following Giddens (1985) and Beck (1986/1992), one theme pursued by surveillance studies scholars has been risk and its responses. If modern living produces risks that are, in the end, incalculable, then surveillance can be seen as a means of reflexivity in the face of these known unknowns. Lyon (2001) argues that surveillance “is the means whereby knowledge is produced for administering populations in relation to risk” (2001: 6). Organizations rely on surveillance processes in order to “minimize risk by finding out as much as possible about as many factors as possible” (ibid. 6). Additionally, as a mode of risk management, surveillance works in at least two ways: “On the one hand, surveillance is seen as a means of minimizing and, if possible, of averting risk. To know in advance is to be forewarned, and to anticipate difficulties or dangers. But on the other hand, surveillance is seen by many as a cause of risk…” (ibid. 46-47).
This feature of surveillance, that it is both a mode of risk management and a producer of risk, is comprehensible in relation to public health surveillance. On the one hand, surveillance is necessary in order to coordinate a response to the risks posed by twenty-first century disease. On the other hand, surveillance may pose a risk to some people, for instance, those targeted for quarantine, or those ostracized because they are associated with a group to whom disease is attributed. Moreover, surveillance also produces risk in another sense – it amplifies the perception of risk. Surveillance does not simply represent risks; rather it forms “part of the technological constellation through which risks come into existence” (Van Loon 2002: 12). Prior to their identification by a surveillance system, isolated cases of a disease are just that… isolated. However, when surveillance processes draw links between these cases, they cease to be isolated and may even become an epidemic.

Hence, while surveillance helps to manage the risks associated with communicable disease, it is also implicated in identifying, and in effect producing, those risks. By abstracting information from its embodied context, by re-assorting this information in the context of a surveillant assemblage, surveillance processes attempt to see what is supposedly latent in the visual register. For instance, Kevin Haggerty and Richard Ericson describe surveillance as “a visualizing device that brings into the visual register a host of heretofore opaque flows of auditory, scent, chemical, visual, ultraviolet and informational stimuli” (2000: 611). Similarly, Lyon suggests that, in order to discern supposedly underlying risk probabilities, “surveillance strips down the complex actions of self-conscious embodied persons to their basic behaviour components” (2001: 150). The rationale for undertaking these abstracting processes is that they will aid in risk management schemes. However, such abstraction generates its own risks.
Because surveillance studies scholars understand surveillance as an abstracting process, they highlight the importance of “informational selves” (Poster 1990: 97), or “data doubles” (Haggerty and Ericson 2000: 613), representations that stand in for those under surveillance. They underscore the fact that these data doubles often serve as markers for access to resources, services and power (ibid. 613). Moreover, while these data doubles are commonly implicated in decisions that enable or constrain chances, those to whom they pertain often have little input into, or understanding of, their creation.

Additionally, and related to the fact that those under surveillance rarely participate directly in the creation of their surveillance information, surveillance studies scholars have identified the tendency of surveillance to proliferate. On this point, the connection between surveillance and the immaterial conception of information is at its most plain. Surveillance systems rely upon information to stand in for the objects under surveillance. They thus engender a paradoxical disappearance and reappearance of bodies and populations (Lyon 2003a: 18). Material bodies (and material bodies politic) are *over-written* and reproduced as informational agglomerates that admit manipulation for management purposes. But these agglomerates both substitute for, and remake, that which is under scrutiny. Consequently, they are always less-than-adequate attempts to objectify the bodies or relationships they are meant to capture. The on-going inadequacy of this information thus engenders a push for ever-more surveillance.

This propensity to proliferate is akin to having enough information to be aware of the existence of a risk, but not enough information to know exactly how to act in relation to this risk. It also relates to precautionary logics, emanating from discourses on security and securitization processes (Zedner 2003; 2008) for example, which have an insatiable appetite for surveillance. In discourse on public health, as in discourse on the environment, these
precautionary logics take the form of the precautionary principle. Consider, for instance, Justice Archie Campbell’s discussion of this principle. The Campbell commission, a commission of public inquiry called by the Ontario government following the SARS outbreak, argued that the precautionary principle instructs decision makers that they need not await scientific certainty before taking measures to reduce risk. Drawing from the Krever inquiry (Canada, Krever 1997), which had investigated the Canadian tainted-blood scandal (see, for instance: Orsini 2002), the Campbell commission argued that a precautionary principle addresses “the problem of underreaction” (Ontario, Campbell 2005: 338). It does so “by pointing out that in the face of a grave risk it is better to be safe than sorry” (ibid. 338). This statement exemplifies the precautionary logics that drive the intensification of surveillance. Better to collect as much information as is possible, these logics hold, than to be subsequently sorry for failing to collect information that may one day be useful.

Note, however, that Campbell favours the precautionary principle because it instructs decision makers not to await scientific certainty before acting. There is an interesting connection between this position and the paradox embodied in the immaterial conception of information. Where the precautionary principle is concerned, the incompleteness of information is both a reason for action, and a reason to collect more information to guide action. Similarly, where the immaterial conception of information is concerned, the apparently static nature of its instantiation, such that it can supposedly transcend space and time, makes it both a reason for, and sought after resource of, IT-mediated surveillance. But what kind of (in)action is surveillance if it is disconnected from its material basis in the pursuit of immaterial information?

Although surveillance scholars have scanned the implications of surveillance systems devoted to the creation of immaterial information, more careful, empirical study is needed.
As I will now argue, the focus on surveillance as a mode of risk management has coincided with a concentration on the surveillance of persons. While the field of surveillance studies has begun to move beyond this concentration, there is presently a dearth of empirical research into surveillance processes that do not have persons as their primary target.

**Surveillance and the Privacy Paradigm**

Certain kinds of surveillance began to make more frequent appearances in North American and European public discourse during the 1960s. For instance, the author of one popular account observed: “Millions of Americans are living in an atmosphere in which peering electronic eyes, undercover agents, lie detectors, hidden tape recorders, bureaucratic investigators, and outrageously intrusive questionnaires are becoming commonplace…” (Packard 1964: 4). Such concerns were connected to the fact that, during the 1960s, bureaucracy and IT began to converge in a manner that changed, in both quantitative and qualitative terms, the way that organizations treated personal information (Bennett 1992). This led to the emergence of Datenschutz (data protection) and information privacy regimes in numerous industrialized states (Bennett 1992; Bennett and Raab 2006). By and large, these regimes have shaped, and been shaped by, “the privacy paradigm” (Bennett and Raab 2006: 14). In other words, they have been oriented towards the protection of personal information and founded upon “an atomistic conception of society [where] the community is no more than the sum total of individuals that make it up” (ibid. 14). Viewed from within the privacy paradigm, surveillance is a problem for individuals.

However, as Priscilla Regan argues, surveillance in the contemporary era is less a technique that persons use in relation to other persons, and more a technique that organizations use to structure relationships with their citizens, clients, employees, patients,
and so on (1995: 213). In view of this contemporary dimension of surveillance, several commentators, some of them firmly rooted in surveillance studies, have questioned the usefulness of information privacy as a response to surveillance (see, for instance: Brin 1998; Etzioni 1999; Lyon 1994; and Stalder 2002). Nonetheless, although surveillance studies scholars have distanced themselves from the privacy paradigm, there remains a preoccupation with the surveillance of personal details. For instance, while wanting to understand the social reasons for surveillance, surveillance studies scholars still tend to define surveillance in relation to personal information. Lyon, for example, defines surveillance as:

…the focused, systematic and routine attention to personal details for the purposes of influence, management, protection or direction. Surveillance directs its attention in the end to individuals (even though aggregate data, such as those available in the public domain, may be used to build up a background picture) (2007: 14).

There are certainly reasons for taking this definition as a starting point, not the least of which is the historical inadequacy of privacy protection as a response to surveillance. Nevertheless, this definition is also indicative of a broader orientation within surveillance studies.

To date, the overriding concern of surveillance studies literature has been with the surveillance of persons. However, as Kevin Haggerty has observed:

…in the contemporary context, an exclusive concentration on studying the process whereby humans are observed neglects an enormous volume of surveillance. An electronic clipping service, for example, sends me a list of references to articles published on the topic of surveillance in the past week. This usually amounts to about 45 references, and only a fraction of them deal with monitoring human beings in any conventional sense. The majority of these articles document surveillance
developments in the world of science and medicine, with titles such as ‘Modeling Human Cancer Genotype-Phenotype Correlations in Mice’, ‘Low Grazing Angle Radar Imaging Experiments Over the South Falls Sandbank’, and ‘Epidemiologic Surveillance and Disease Control’ (2006: 30).

These forms of surveillance, however, tend to lie on the margins of surveillance studies. The fact that surveillance has been pegged to the privacy paradigm in popular discourse is certainly one reason for the marginalization of some kinds of surveillance within the field. Another reason, perhaps a larger reason, has to do with theoretical legacies that lean surveillance studies towards issues involving personal information. Foucault’s work, not just on Jeremy Bentham’s Panopticon, but also on governmentality, makes up a large part of the theoretical foundation of surveillance studies. There has been some notable critique of the influence of the Panopticon in surveillance studies (Boyne 2000; Haggerty and Ericson 2000; and Lyon 2006). However, less critical attention has been focused on the preoccupation with governmentality and responsibilization. Below I will briefly introduce the concept of governmentality and describe its relation to the idea of responsibilization. I think the preoccupation of surveillance studies scholars with this idea is a further reason for the neglect of certain kinds of surveillance.

**Surveillance and Responsibilization**

To get away from the form of analysis that consists in “reducing the state to a certain number of functions” (Foucault 1979/1991: 103), Foucault suggested that a history of governmentality might concentrate on the following:

1. The ensemble formed by the institutions, procedures, analysis and reflections, the calculations and methods that allow the exercise of this very specific albeit complex form of power, which has as its target population, as its principal form of knowledge political economy, and as its essential technical
means apparatuses of security. 2. The tendency which, over a long period and throughout the West, has steadily led towards the pre-eminence over all other forms (sovereignty, discipline, etc.) of this type of power which may be termed government, resulting, on the one hand, in the formation of a whole series of specific governmental apparatuses, and, on the other, in the development of a whole complex of saviors. 3. The process, or rather the result of the process, through which the state of justice of the Middle Ages, transformed into the administrative state during the fifteenth and sixteenth centuries, gradually becomes ‘governmentalized’ (Foucault 1979/1991: 102-103).

Foucault’s concern was to understand both government and its conditions of possibility. His articulation of governmentality sparked a line of inquiry into the various ways governed subjects themselves take on, and are encouraged to take on, the responsibilities of government, thereby engaging in self-governing practices.

Nikolas Rose argues, for instance, that, at the start of the 20th century, two responsibilization strategies began to take shape across Europe, North America, and their colonies. The first was concerned with the maximization of the fitness of the population by the individualized attention to habits of subjects. The second was concerned with maximizing the fitness of the population by focusing on reproduction, through eugenics, for example. However, Rose asserts, these strategies are different today. They are no longer inspired by the dream of taking charge of the lives of each in the name of the destiny of all. “In this new configuration, the political meaning and salience of health and disease have changed” (2001: 5). Rose argues:

The contemporary state does not ‘nationalize’ the corporeality of its subjects into a body politic on which it works en masse, in relation to the body politics of other states competing in similar terms. […] Instead] images now are of the enabling state, the facilitating state, the state as animator. On the one hand, the state retains the responsibility that it acquired in the 18th and 19th century - the precise
timing varying across national contexts - to secure the general conditions for health: regulating the sale of foodstuffs, organizing pure water and sewage disposal, sometimes mandating the addition of health-promoting elements into the diet - vitamins, fluoride in water and the like. On the other hand, within such a health-promoting habitat, the state tries to free itself of some of the responsibilities it acquired across the 20th century for securing individuals against the consequences of illness and accident (2001: 6).

This line of inquiry, pursued by Foucault and his commentators, has inspired a range of studies concerned to detail the numerous subtle, and not-so-subtle, strategies designed to responsibilize individual citizens. Several of these, following Foucault’s seminal investigations of medical power (for instance: 1961/1988; 1963/2003; 1976/1980; 1976/1990; and 1977/1980), have sought to understand how medical care and public health practices are implicated in the governance and responsibilization of people (for instance: Armstrong 1983; Cheek and Rudge 1994; Crawford 1994; Epling et. al. 2003; Fitzpatrick 2001; Gibson 2004; Lupton 1995; McKie 1995; Petersen and Bunton 1997; Porter 1999; and Turner 1992).

Additionally, surveillance studies scholars have explored the role of surveillance in relation to responsibilization. For instance, giving Beck’s risk thesis a Foucaultian spin and highlighting the “utilitarian morality” of the so-called risk society, Richard Ericson and Kevin Haggerty observe an impetus to download governance: “The onus is placed on organizations and individuals to be more self-sufficient, to look after their own risk-management needs” (1997: 6). These conditions, they argue, engender the institutional structuration of organizational and individual trajectories. The result is a “combination of pervasive surveillance devices, precise regulation of movement through territories, and aesthetically pleasing design,” all of which embeds coercion making it “subtle, and therefore
not experienced as coercion at all” (ibid. 7). Following a similar line of argument, Clive Norris and Gary Armstrong link the rise of Closed-Circuit Television surveillance to responsibilization. They observe the emergence of “a new form of penology based on ‘actuarial justice’,” and the “abandonment of individualised suspicion” (1999: 26; see also Freeley and Simon 1994: 180-5). Without wanting to do injustice to the nuances of their analysis, one may still discern an overarching concern; the worry is that the right to be presumed innocent will subtly be replaced by the onus to prove one’s innocence in a society where all are presumed guilty.

It is tempting to overlay the criminological analysis of surveillance onto the public health context, and to wonder whether an increase in public health surveillance equals a presumption that populations are ill until proven healthy. Certainly, Foucault’s work provides a matrix in which to connect these biopolitical dots. His presentation of Bentham’s Panopticon, after all, begins with a discussion of quarantine and plague management (1975/1995: 195-198; see also Elden 2003). However, without wanting to deny the imbrication of biopolitics and public health surveillance, the picture is somewhat more complex and ambivalent.

Arguably, this complexity and ambivalence has kept the subject of public health surveillance on the margins of surveillance studies. This is not to say that there are no surveillance studies resources for the study of public health surveillance; quite the contrary, as I will show below. However, public health surveillance does present difficulties for a surveillance studies concentrated on personal information. For instance, how does one factor subjectivity-transformation into situations where people are unaware that they are under surveillance? Additionally, how does one approach surveillance systems that do not target personal information (for example, the West Nile Virus surveillance system, which
tracks the death of birds)? Nevertheless, precisely because of this complexity and
ambivalence, a surveillance studies approach to public health surveillance can yield novel
insights, not only about public health surveillance, but also about surveillance studies more
generally. Below, and in the next chapter, I draw on resources both within and beyond
surveillance studies in order to position the analysis undertaken in this dissertation.

Towards a Surveillance Studies Approach to Public Health Surveillance

Although public health surveillance has not been a core focus of surveillance studies to date,
several interesting social scientific critiques of surveillance in medical care and public health
contexts have been written. A distinction may be drawn between two kinds of critique. The
first critique attempts to theorize the effects of the expansion of surveillance. David
Armstrong’s (1995) article, “The Rise of Surveillance Medicine,” exemplifies this kind of
critique. Armstrong chronicles the gradual displacement of what he calls Hospital Medicine, by
a new form of medicine: Surveillance Medicine. According to Armstrong, Hospital Medicine
had reconfigured earlier ways of thinking about illness. Before Hospital Medicine, he
contends, a patient’s illness was coterminous with the symptoms that he or she reported.
Hospital Medicine reconfigured the relationship between symptom and illness by
supplementing, and sometimes supplanting, the patient’s experience with the physician’s
interpretation. In the twentieth century, Armstrong argues, Hospital Medicine began to be
replaced by a new kind of medicine, a medicine based on the surveillance of ‘normal’
populations. Armstrong argues:

This new Surveillance Medicine involves a fundamental remapping of the spaces of illness. Not only
is the relationship between symptom, sign and illness redrawn but the very nature of illness is
reconstrued. And illness begins to leave the three-dimensional confine of the volume of the human body to inhabit a novel extracorporal space (1995: 395).

This transformation involves strategies of health promotion, including “giving responsibility for surveillance to patients themselves” (ibid. 399). It also involves getting ahead of the symptom, looking for markers of illness in risk factors that might precede the emergence of symptoms, such as supposed genetic predispositions. For Armstrong, illness is placed within a wider spatio-temporal context by *Surveillance Medicine*. His concern is with the effects of this transformation, not the least of which is the growing responsibilization of patients.

The second critique focuses on the specifics and efficacy of particular surveillance systems. Here, questions about the precise kinds of information collected and produced by surveillance, as well as about the politics and ethics of these choices, are in the foreground. Nancy Krieger’s (1992) article, “The Making of Public Health Data: Paradigms, Politics, and Policy,” exemplifies this kind of critique. Krieger argues that data are less reflections of what is known, and more reflections of decisions, made by individuals and institutions, which “embody underlying beliefs and values about what it is we need to know in order to understand population patterns of health and disease” (Krieger 1992: 413). Accordingly, the way public health information is collected and reported profoundly effects how public health professionals, and the public in general, perceive health problems. The consequences of selectively privileging some kinds of information over others are nicely suggested by Krieger, using the example of infant mortality:

Label infant mortality a problem of ‘minorities’ and present data only on racial/ethnic differences in rates, and the White poor disappear from view; label it a ‘poverty’ issue and proffer data stratified only by income, and the impact of racism on people of color at each income level is hidden from sight;
define the ‘race’ or socioeconomic position of the infant solely in terms of the mother’s characteristics, and the contribution of the father’s traits and household class position to patterns of infant mortality likewise will be obscured (ibid. 412).

From this example, it is apparent that the choice of which information goes into a surveillance system shapes the kind of information that comes out of that system. Krieger captures the issue succinctly: “there is far more to public health data and data bases than meets the eye – and usually what is missing is of key significance” (ibid. 421). Whereas Armstrong’s critique considers the implications of the expansion of surveillance, Krieger’s considers the implications of its contraction.

My own view is a hybrid of these two different kinds of critique. From the first kind of critique I adopt a skepticism towards the assumed inherent goodness of expanded, intensified surveillance. The limitation of this kind of critique, though, lies in its homogenization of surveillance. Consequently, from the second kind of critique I take an orientation towards detail, and a focus on the kinds of information produced by surveillance systems. While the first kind of critique seeks to limit surveillance, and the second kind of critique seeks to expand it, I think a middle-ground is preferable. More information needs to be collected, for instance about the broader determinants of health, or about the trajectories of certain diseases, and this does call for an intensification of surveillance. However, such an intensification must, I believe, be locally and democratically directed. Questions as to what constitutes a problem for health surveillance, and for whom, need to be continually revisited.

Such questions need to be continually revisited because the data generated by health surveillance, and indeed, health surveillance systems themselves, may permit a variety of secondary and tertiary uses. For instance, such information may well be used to discriminate against people according to biological characteristics, such as race (Poudrier 2003; Wiebe
2008). Or, it may be used to regulate work practice in medical care and public health contexts (Cole 2006; Monahan and Fisher 2008). Or, it may become enrolled in *de facto* identity card schemes (Wilson 2008). Or, it may join the assemblage of biometric and genetic surveillance initiatives meant to take identification schemes to the next level, be they at the border, in the criminal justice system, or in the insurance marketplace (for instance: Lyon 2008; Muller 2005; van der Ploeg 2003 and 2005; and Zureik and Hindle 2004). The list of such uses goes on. Indeed, one of the strengths of surveillance studies has been to anticipate alternate uses for surveillance systems, and the function creep that commonly attends their development (Nelkin and Andrews 2003).

Hence, surveillance studies offer numerous touchstones for an analysis of public health surveillance. However, as I will argue, the preoccupation with personal information in surveillance studies has left a swath of assemblages, both above and below the level of the individual person, on the margins of inquiry. Nevertheless, the complexities and ambivalences of public health surveillance make an investigation into these assemblages necessary. As a substantive area of inquiry, therefore, public health surveillance presents a case that calls for a novel mode of analysis. The analytic mode I develop in this dissertation will, I hope, interest surveillance studies scholars wanting to analyze surveillance processes that do not have persons as their primary target.

One of the key tools for accomplishing this analysis, I argue, is lying somewhat latent in surveillance studies. While surveillance studies scholars have linked the rise of surveillance to the rise of information, and while they have theorized the implications of systems that abstract information from its local, embodied and embedded context, the significance of the connection between surveillance and the immaterial conception of information remains under-theorized. Insofar as surveillance is about the collection of
information for the purpose of guiding future action, surveillance processes are invested in, and champion, the immateriality of information. That is, using classifications, categories, taxonomies, nomenclatures, and so on, surveillance processes abstract information from its material setting in order to render it useful across space and time.25

Literature in surveillance studies has concentrated on the effects of taking information out of context. However, only a minority of surveillance studies scholars have dealt with the widespread assumption that IT-mediated surveillance makes information immaterial, endowing it with a spacelessness and timelessness so as to permit comparability and the minimization of uncertainty in decision-making processes. Irma van der Ploeg is among the minority to have probed the limitations of the assumption that that IT-mediated surveillance makes information immaterial. Her critique of biometric technology asserts that there “is no clear point where bodily matter first becomes information” (2003: 69). Consequently, the demarcation between body and information “cannot be adequately understood as a boundary between the thing itself and representations of it” (ibid. 69-70).

Lyon (2008) has elaborated this argument, questioning the body/data distinction common in legal and academic discourse. Surveillance of the body, he notes, tends to assume two kinds of stability. First, the body itself is assumed to be a stable entity, a better source of identification than, say, a social insurance card. Second, the relationship between the body and its information is assumed to be stable. It is precisely the assumption that information is immaterial that permits such assumptions about the stability of body-based surveillance. However, as Lyon writes: “hype about the supposed immateriality of information circulating in today’s digital media clouds discussion of what is actually going on” (2008: 506).

In the chapters to follow I undertake an exploration of what is going on in public health surveillance. I do so by exploring the material dimensions of information, the
materiality that permits information to course through surveillance systems. In so doing, I aim to extend the nascent surveillance studies analysis of the materiality of information set out by van der Ploeg and Lyon. However, instead of taking personal information as a point of departure, I introduce, in the next chapter, a different analytical frame – the local order of concern. This scalable analytic frame permits a consideration of the different assemblages involved in the processing of information.

Conclusion

Immaterial information is paradoxical. The rise of this paradoxical conception coincides with a process whereby it has become possible to conceive of material using an immaterial conception of information. At the same time that matter was being translated into information, information supposedly became immaterial.

This transformation is exemplified in the domain of twentieth-century genetics. In a sequential process whereby nature became biologized, biology became geneticized, and genetics became informationized (Franklin et. al. 2000: 188-189), the ‘secret of life’ seemed to have been progressively unwrapped. The genetic code was hailed “as the long awaited synthesis of all the venerable antitheses in the study of life, legitimized by breathtaking advances in molecular biology and by integration with well-elaborated vocabulary of information systems technology…” (Oyama 1985/2002: 16). Twenty-first century genetics, however, reveal a different picture of the code, complicating the rigid distinction between gene and protein (Fox Keller 2000), between the immaterial and the material. As Hayles poignantly observes:

DNA is often understood to operate as a digital code, in the sense that it is discrete rather than continuous. With the sequencing of the human genome, however, it has become clear that sequence
is only part of the story, perhaps even the less important part. Protein folding, an analog process that makes use of continuous transformation in form, is essential to understanding how the genome actually functions. The combination of the two processes, the digitality of DNA sequences and the analog process of protein folding, gives the gene its remarkable power of information storage and transmission. Similar cooperations between digital and analog processes occur everywhere in nature and in contemporary technologies (2005: 29).

Accordingly, discourse in twenty-first century genetics is extricating itself from the dominating, rigid binary between the material and the immaterial; the same cannot be said, however, for euphoric discourse on IT-instantiated information. As this chapter has illustrated, an immaterial conception of information remains alive in discourse that promotes investment in IT. This conception encourages, and is encouraged by, the intensification of surveillance.

As I have argued in this chapter, immaterial conceptions of information foster the supposition that information can stand outside of space and time. This is evident in Wiener’s conception of information, which is set apart from matter. It is also evident in Castells’ discussion of IT-instantiated information. The Romanow, Kirby, and Naylor Reports, while less explicit about the im/materiality of information, put an unwarranted faith in the ability of IT to resolve crises faced by the medical care and public health systems. Their positions, however, are not without consequence, as I will demonstrate in coming chapters.

In order to stage the subsequent analysis, I reviewed literature from surveillance studies and argued that this field contains some excellent resources for exploring the material dimensions of information in public health surveillance systems. However, the field of surveillance studies also has some gaps. Chief among these is that, as a comparatively young
field, there is as yet a dearth of empirical research on public health surveillance. This dearth might also be explained by a preoccupation, in the field, with certain kinds of surveillance, namely surveillance that primarily targets personal information.

In the next chapter I consider ideational and institutional reasons that have made attempts to immaterialize information so central in a public health context. Additionally, I set out a new analytical frame — the local order of concern — in order to broaden the surveillance studies approach beyond its focus on personal information.
Chapter 3: Public Health Surveillance and War-Time Mentalities

In 1951 the United States (US) Department of Defense and the US Federal Civil Defense Administration aired a television program entitled *What You Should Know About Biological Warfare*. The program featured Alexander Langmuir, a decisive figure, as it turns out, in the history of public health. In the program, Langmuir presented a frightening picture of the precise ways in which biological weapons could be deployed in attacks against the United States. He also made the case for a public health system that could defend against this threat. Elizabeth Fee and Theodore Brown give the following description:

> At one point in the program, Langmuir turned on a Waring blender filled with dry ice for a vivid demonstration of how clouds of aerosol mist could contaminate a whole studio and infect everyone inside. He then used a familiar can of insecticide to demonstrate the working of an aerosol spray. Employing much the same principles, he said, an enemy could mount aerosols on airplanes and cover a city with a vast cloud of infectious material. Langmuir also injected colored liquid into a model of the water supply of a city to show how easily a biological warfare agent could spread. How could anyone protect or defend against such an attack? [...] In short, he said, the country needed an epidemic intelligence service (2001: 722-723).

Langmuir was able to successfully capitalize on fear about biological warfare by capturing the political will and funding for one of the most comprehensive public health surveillance undertakings in the world. His creation of a highly trained cadre of disease detectives, and the institutional apparatus to support them, stands out amongst the achievements in the history of American public health. To some, Langmuir’s use of the biological warfare issue to build public health infrastructure amounted to making the best of a bad situation.27 To
others, it narrowed the scope of epidemiology to a focus on infectious diseases “that were not of any real threat to [the population] outside of their presumptive use as biological weapons” (ibid. 725). Regardless of one’s position on this issue, it is noteworthy that the person who first popularized the use of the term surveillance in a public health context should have done so against the backdrop of fears over biological warfare, and in a political context where staunching the spread of communism was every bit as urgent as staunching the spread of germs.

In this chapter I argue that the legacy of the association between war and public health is a lasting circumscription of the meaning of public health surveillance. While surveillance has long been imbricated with warfare (see, for instance: Dandeker 1990 and Graham 2006), this association is probably not the first to come to mind when considering surveillance in a public health context. Nonetheless, the warfare metaphor has a long history in discourse about the health or illness of bodies, and it is possible to see a war-time mentality at work in the backdrop of some contemporary articulations of public health surveillance. In pragmatic terms, this engenders a kind of surveillance focused so heavily on disease that the broader determinants of health are left out of the picture (Krieger 1992 and 1994).

In the first section of this chapter, drawing from the history of the US Centers for Disease Control and Prevention (CDC), I sketch Alexander Langmuir’s creation of the US Epidemic Intelligence Service (EIS), as well as his articulation of surveillance in relation to disease. Additionally, I show how Langmuir’s Cold-War–era definition remains embedded in contemporary articulations of public health surveillance. In the second section, I consider discourse concerned with emerging infectious disease, focusing in particular on HIV/AIDS.
This discourse moves the concept of public health surveillance from an ideological to an ontological frame of reference, making it at once more expansive and superficial.

With these two vignettes, my intent is to suggest that the concept of public health surveillance is imbricated with war-time logics. The thematic of war, not necessarily just between nation-states, but also between an imagined humanity and an army of microbes, fosters ideational and institutional tendencies towards an all-or-nothing approach to disease. These tendencies are simultaneously totalizing and reductionist; they admit no nuance. Moreover, they mesh with the immaterial conception of information; on the one hand they foster the pursuit of immaterial information and on the other hand they are underwritten by this conception’s binary logic. In the final section of this chapter I argue that such tendencies marginalize local orders of concern. Before proceeding further, it will first be worthwhile to explain precisely what is meant by this phrase.

The phrase expands upon a distinction, drawn by Latour, between matters of fact and matters of concern. Latour writes: “Matters of fact are not all that is given in experience. Matters of fact are only very partial and, I would argue, very polemical, very political renderings of matters of concern, and only a subset of what could also be called states of affairs (2004: 231). This distinction is compelling, but I substitute the phrase local orders of concern for states of affairs in order to indicate that matters of concern are irreducibly contextualized by the spatio-temporal register in which they are lived. In other words, matters of concern are articulated within local orders of concern, the material assemblages that actualize concerns. To abstract a state of affairs from these local, material orders is to immaterialize the conditions of their concerns.

The term “local” in the phrase local orders of concern is meant to inject a degree of relativism into matters of concern (and, consequently, into matters of fact). This is not to say
that all matters of fact are relative; rather, it is to suggest that matters of fact will be
differently inflected according to the locale from which they emanate. Here, the term
“local” is scalable. It highlights the fact that matters of concern have as much to do with
perception as they do with articulation. In other words, matters of concern are amplified or
not according to whether, and how, they come under surveillance.

In pragmatic terms, the study of local orders of concern broadens the surveillance studies
approach beyond its traditional focus on personal information. For example, this focus
expands the consideration of exactly who, or indeed what, is marginalized by surveillance.
The marginalization of patients by medical authority has long been a concern of scholars in
the social sciences and humanities (see, for instance, Illich 1976). My interest here, however,
is not only with the marginalization of patients. Their marginalization is bound together
with, and compounded by, two other less obvious kinds of marginalization. Hence, I have
in mind three related local orders of concern when I consider marginalization. Most
obviously, patients are marginalized – or better, vectorized – insofar as they are reduced by
surveillance to a matter of association. That is, they are marginalized by processes that
reduce them to vectors of disease. In a related vein, just as patients are reduced to a matter
of association, their microbes are marginalized insofar as they are reduced, by surveillance, to
a matter of distribution. The marginalization of these two local orders of concern is
problematic because, to the extent that microbial and patient heterogeneity are beyond the
scope of surveillance, the public health response will be inadequate, leaning less towards
care-oriented interventions and more towards control-oriented interventions.

However, it is necessary to make a caveat at this point. Control-oriented public
health surveillance is subject to contestation, not only by patients but also by practitioners.
And yet, such contestation is effaced if it is subsumed under the immaterial conception of
information. Take, for instance, the way that war-time crisis mentalities promote the use of information technology to automate public health surveillance. These mentalities tend to disregard the labor that makes information technology work. In short, they neglect the actual spaces of negotiation and contestation in which public health surveillance is performed. As a result, it is crucial for a surveillance studies analysis to understand that a third local order of concern – the local, organizational order – is similarly marginalized by the crisis-driven pursuit of immaterial information. I substantiate these claims in chapters 4, 5, and 6, following a brief introduction to them here.

The Cold-War-Era: The Development of American Public Health Surveillance

In 1949 Alexander Langmuir left an academic posting at the Johns Hopkins School of Hygiene and Public Health to take up a job at the then fledgling CDC. At the time, the CDC still had a sizeable staff of entomologists and engineers, and was spending about 7 million USD per year spraying dichloro-diphenyl-trichloro-ethane (DDT) in order to control malaria. Langmuir felt that malaria had been eradicated by this point, and that the DDT effort was unnecessary. Suspecting the over-reporting of malaria cases, Langmuir proposed that a four member team be assigned to states with a malaria problem. The team was to consist of a nurse-epidemiologist, an epidemiologist, an engineer, and an entomologist. The epidemiologists were to investigate each case, confirming it by laboratory diagnosis. Once confirmed, the engineer and the entomologist would initiate appropriate control measures.

Langmuir’s innovation subtly put the emphasis on epidemiological investigation, and changed the case-reporting structure. As Elizabeth Etheridge notes, instead of having doctors report “the number of cases of malaria they had seen – an easy diagnosis – they had to supply names” (1992: 33). This new mode of investigation appeared to drastically reduce
the number of malaria cases. Whereas in 1947 some 15,000 malaria cases had been reported, by 1950, under Langmuir’s new system, only 55 positive cases were identified (ibid. 34). Etheridge argues that Langmuir’s malaria initiative was the first use of surveillance applied to a disease in US public health. “Until those first teams went out from the CDC,” she writes, “surveillance in public health meant watching persons who had been in contact with certain serious diseases like plague or smallpox or syphilis to detect the first symptoms so that the patient could be isolated. Beginning in 1950, the term was applied to specific diseases rather than to individuals” (ibid. 35). This claim rests on a very circumscribed definition of health surveillance, a definition that I will discuss below. Suffice it to say here that most surveillance study scholars define surveillance differently than the way it is commonly defined in public health discourse. This is one of the reasons why Langmuir stands out in the history of public health.

In addition to bringing his experience with epidemiological methods and surveillance to the CDC, Langmuir brought experience garnered while serving, after the Second World War, on the US Department of Defense’s Committee on Biological Warfare. This position had given him high-level security clearance, and an intimate knowledge of threats posed by biological weapons (Fee and Brown 2001: 722). It also meant that Langmuir was ideally positioned to take a leadership role in America’s response to the perceived threat of biological warfare. By 1951, it was the CDC – rather than the National Institutes of Health (NIH) – that had assumed responsibility for protecting against an attack involving biological weapons. The Department of Defense provided the CDC with funding for some of this work, which included the development of air-sampling devices and laboratory techniques for the rapid detection and identification of pathogens. The epidemiological unit was also to
play a crucial role in responding to the threat of a biological weapons attack. It would be tasked with correlating air quality findings with observed human illness (Etheridge 1992: 39).

In 1950, the CDC did not have the institutional resources necessary for such an undertaking. However, with the outbreak of the Korean War in June of that year, things began to change. Although the US government ordered all non-defense budgets scaled back, the CDC was able to attract resources for epidemiological work by framing it in terms of “intelligence” (Fee and Brown 2001: 722). This gave the work of the CDC a covert ring, making the undertaking seem more exciting and attracting a number of physicians to a year-long disease-detective course, instituted in 1951 (Etheridge 1992: 44). By 1952, the Epidemic Intelligence Service (EIS), as the unit came to be known, was in its first full year of service. It responded to over 200 calls for aid by local public health officials that year. Initially, there was some worry that the CDC’s EIS would have some jurisdictional friction with epidemiologists from the NIH. For this reason, Langmuir maintained frequent communication between Bethesda (where the NIH is headquartered) and Atlanta (where the CDC is headquartered). “To keep everyone informed,” Etheridge writes, “a simple administrative device, the Epidemic Aid Memorandum, was created. The day a request for help came in and a team organized to respond, an ‘Epi 1’ memo was sent to officials with a ‘need to know’” (ibid. 47).

This historical sketch highlights two key moments in the development of the concept of surveillance in a public health context. First, the idea that surveillance applies to disease, rather than to individuals, distinguishes surveillance, for public health purposes, from control activities. This de-linking of surveillance from control is an ideational innovation that will be significant to surveillance studies scholars. Thus formulated, surveillance itself takes on an aura of immateriality; this appears to set the stage for its de-
politization. However, the second key moment highlighted above was, decisively, political. Langmuir’s use of defense funding institutionalized a surveillance concentrated on epidemic disease. It was a circumscribed, war-time, crisis-driven surveillance, predicated on the immanence of disaster.31

This Cold-War–era mark remained in subsequent articulations of surveillance in a public health context, even as the Cold-War faded into the historical background. In 1962, Langmuir delivered the Cutter Lecture on Preventative Medicine at the Harvard School of Public Health. The lecture, which was later published in the New England Journal of Medicine, laid down the basic definition of surveillance in a public health context. Framing his remarks in relation to the work of William Farr, “that greatest of statistical epidemiologists” (Langmuir 1963: 182), Langmuir states:

The term surveillance […] is not new to public health, but its usual connotation has had application to individuals rather than to diseases. Surveillance, when applied to a person, means close observation to detect the early signs of infection without restricting his freedom of movement. It implies maintaining a responsible alertness, making systematic observations and taking appropriate action when indicated. It does not involve the restrictions of either isolation or quarantine. Surveillance, when applied to a disease, means the continued watchfulness over the distribution and trends of incidence through the systematic collection, consolidation and evaluation of morbidity and mortality reports and other relevant data. Intrinsic in the concept is the regular dissemination of the basic data and interpretations to all who have contributed and to all others who need to know. The concept, however, does not encompass direct responsibility for control activities. These traditionally have been and still remain with the state and local health authorities (ibid. 182-183 -emphasis mine).

The italicized words in the above passage are picked up in the next generation of definitions, especially by Stephen Thacker.
Thacker is currently director of the CDC’s Office of Workforce and Career Development. He also served as an Epidemic Intelligence Officer in Washington, DC between 1976 and 1979. Thacker’s academic work has been instrumental in framing surveillance in public health, both in America and abroad. He has published widely on public health surveillance and is frequently cited. In an article on public health surveillance in the United States, written in 1988, Thacker and his colleague Ruth Berkelman observe:

...Langmuir defined disease surveillance as “the continued watchfulness over the distribution and trends of incidence through the systematic collection, consolidation and evaluation of morbidity and mortality reports and other relevant data” and the regular dissemination of data to “all who need to know” (164 -citation omitted).  

Thacker and Berkelman drew this quotation from Langmuir’s 1963 article, cited in the previous paragraph. My quotation of Langmuir highlights the exact words that are picked up by Thacker and Berkelman. I think the difference between the two passages – especially what is missing in the Thacker-Berkelman (1988) version – is telling.

Thacker and Berkelman drew this quotation from Langmuir’s 1963 article, cited above, and argued that the concept of public health surveillance has broadened, over time, to include a wider range of health information. However, whereas the range of information collected has broadened, the range of those involved in setting public health surveillance priorities has not. Note which of Langmuir’s words pass into the Thacker-Berkelman articulation of public health surveillance. The continued presence of the (slightly modified) key phrase ‘all who need to know’ raises an interesting set of questions. Who are those who need to know? What do they need to know and why? Additionally, who determines what is
included in the range of health information under surveillance? Langmuir’s definition included the phrase ‘all who have contributed,’ but, by the time Thacker and Berkelman define public health surveillance, these contributors, whoever they may be, are dropped. This is significant, especially as the Langmuir-Thacker-Berkelman formulation is being globalized.

In Canada, for instance, two recent documents define surveillance in a public health context in similar terms. After the SARS outbreak, the Naylor Report (discussed in chapter 2) gave the following definition:

Health Surveillance may be defined as the tracking and forecasting of any health event or health determinant through the continuous collection of high-quality data, the integration, analysis and interpretation of those data into surveillance products (for example reports, advisories, alerts, and warnings), and the dissemination of those surveillance products to those who need to know (Canada, NAC, 2003: 92 -emphasis mine).³³

Similarly, the Public Health Agency of Canada, which was created following the SARS outbreak, produced a document to help public health managers evaluate surveillance systems. The definition is as follows:

Health surveillance can be described as “the tracking and forecasting of any health event or health determinant through the continuous collection of high quality data, the integration, analysis and interpretation of … data into surveillance products … and the dissemination of … surveillance products to those who need to know [to address] a specific public health purpose or policy objective.” Health surveillance is an essential component of evidence-based decision making practices (Canada, PHAC 2004: 3 -emphasis mine, ellipses and square brackets original, note omitted).
These definitions bear the Cold-War–era mark. As I shall now argue, this mark takes on increasing and changed significance in an era of growing interest in global disease surveillance.

*The ‘Age of Globalization’: The Development of Global Disease Surveillance*

A war-time ethos characterized the ideational and institutional development of public health surveillance in America. The terms of this war-time ethos, however, have changed. Today’s wars – the war on terrorism is the key exemplar, but it was presaged by the war on drugs, not to mention the war on cancer – admit “increasingly little difference between outside and inside…” (Hardt and Negri 2004: 14). Such wars further blur already fuzzy juridical boundaries between so-called normal conditions, and those conditions deemed to be exceptional. Moreover, according to Giorgio Agamben, this blurring of boundaries is itself becoming normalized (2003/2005: 2). In his words, “the state of exception has today reached its maximum worldwide deployment” (ibid: 87). Ultimately, Agamben argues, the normalization of the state of exception makes “the very distinction between peace and war […] impossible” (ibid: 22). Although some have been critical of Agamben for overestimating the extent to which the state of exception has become normalized, his work nonetheless draws attention to the proliferation of those processes that paradoxically undermine control in attempts to exercise control.

In this section, I consider *emerging infections disease* discourse as an exemplar of this kind of paradox. This discourse reconfigures Cold-War–era mentalities, extending the conditions of struggle beyond the bounded nation-state. It proffers global solutions aimed at controlling microbial enemies and protecting (an imagined) humanity. At the same time, it
highlights the fragility of this humanity. This discourse relies upon strong distinctions between the human and its apparent microbial enemies; it denies the excessive “species-meeting” and “ambivalence towards difference” evidenced by the symbiotic processes that constitute microbe-humans as assemblages (Hird 2008: 21-33). Emerging infectious disease discourse is more about process than end product – it is the perfect motivator for an intensification of surveillance.

The archetypal emerging infectious disease is HIV/AIDS. On June 5th, 1981, the US CDC’s *Morbidity and Mortality Weekly Report*, detailed the deaths of “5 young men, all active homosexuals” (US CDC 1981: 250). As links began to be made between these and other cases, the American media started reporting a *gay pneumonia*, then a *gay cancer*, and finally a *gay plague* “when the list of attendant infections grew too numerous to include in a headline” (Patton 1985: 5). By 1982, these cases had been drawn together under the rubric of AIDS, Acquired Immune Deficiency Syndrome (Grmek 1990: 32), a term selected to replace the informally circulating *Gay Related Immune Deficiency* moniker (Treichler 1999: 27).

Of course, AIDS was never a disease particular to “homosexuals”. Increasingly, heterosexual and non-sexual behaviours came to be understood as risky. At the same time, blame came to be increasingly apportioned by the heteronormative mainstream to those already marginalized by the disease (Grmek 1990: 39). The concomitant generalization of the epidemic and intensification of exclusion had, as many have argued, several transformative effects. Ilona Kickbusch argues that HIV/AIDS transformed public health into a global endeavour: “No longer was there a clear separation between diseases of the rich and poor; the simple division between a developed world with chronic conditions only and a developing world with infectious diseases no longer applied” (2007: xi).
Moreover, Kickbusch argues, this transformation was accompanied by other dimensions of concern:

…the rapid spread of HIV/AIDS was no longer considered just a health risk, it was defined as a security concern of global dimensions. National intelligence reports were written on the threat that could emerge from states that collapsed into anarchy due to high rates of the disease and HIV/AIDS was taken to the United Nations Security Council as the first ever health issue (ibid. xi-xii).

As Joost Van Loon observes, the cultural politics of HIV/AIDS became the cultural politics of infectious disease. “From here,” he writes, “it is only a small step to the development of a more general public concern over emergent viruses. AIDS provided merely the index case – a new disease that was unknown, lethal, contagious and globally present” (2002: 137-138).

In 1992, the American Institute of Medicine released a now famous report entitled *Emerging Infections: Microbial Threats to Health in the United States*. The report opens with the following lines:

As the human immunodeficiency virus (HIV) disease pandemic surely should have taught us, in the context of infectious diseases, there is nowhere in the world from which we are remote and no one from whom we are disconnected. Consequently, some infectious diseases that now affect people in other parts of the world represent potential threats to the United States because of global interdependence, modern transportation, trade, and changing social and cultural patterns (Lederberg et. al. 1992: v).

This situation, according to the authors of the report, makes “the battle against infectious disease” (ibid. v –emphasis mine) exceedingly difficult. Moreover, while drugs, vaccines and pesticides are important “weapons,” their use “may inadvertently contribute to the selection
of certain mutations, adaptations, and migrations that enable pathogens to proliferate or nonpathogens to acquire virulence” (ibid. v).

As a consequence, disease surveillance is held, by the authors, to be of the utmost importance. A considerable portion of the Emerging Infections report is devoted to the need to strengthen surveillance capacity, both inside and outside of the United States. For instance, the report states: “The key to recognizing new or emerging infectious diseases, and to tracking the prevalence of more established ones, is surveillance” (ibid. 2). Additionally, the “importance of surveillance to the detection and control of emerging microbial threats cannot be overemphasized. […] Surveillance is important to any disease control effort; it is absolutely essential if that effort’s goal is eradication” (ibid. 115). Note the all-or-nothing language.

As Nicholas King (2002: 768) observes, this report became the centerpiece of a major global public health campaign. Largely in response to this report the WHO established a special division for communicable-disease surveillance. This division was tasked with improving national surveillance systems, as well as coordinating with non-governmental organizations, expert advisors, and collaborating centres. The WHO also initiated the Global Outbreak and Response Network, which was launched in 2000 and which links institutions and coordinates outbreak response (Weir and Mykhalovskiy 2006: 246-247; see also Mykhalovskiy and Weir 2006). These institutional developments paralleled regulatory initiatives, such as the recently revised International Health Regulations (WHO 2005).36

The adoption of these regulations took on a new urgency in the wake of the SARS outbreak, with many public health experts arguing that they “were urgently needed to help protect ‘the global village from pandemic influenza’” (Fidler 2005: 2 -note omitted).
Although the globalization of public health measures is laudable, serious ethical and political questions attend the globalization of disease surveillance. Who, for instance, will benefit? Some have argued that these developments are merely another iteration of the neoliberal globalization of capital. For instance, for Michael Hardt and Antonio Negri, the discourse on emerging infections is merely another indication that the crisis of modernity has reached its apogee. “The age of globalization,” they assert, “is the age of universal contagion” (2000: 136). Fleshing out their less-than-nuanced formulation, Alison Bashford notes that globalization and disease management are related in at least three ways. First, travel has increased and accelerated the transborder migration of microbes. Second, information technologies have been used to track disease outbreak regardless of the limitations placed on classical epidemiological methods by international boundaries. Third, the idea of surveillance development “as a way to secure disease-free regions” (Bashford 2006b: 11), now represents the westernization component of globalization. These underlying processes play key roles in the production of anxieties that motivate the desire for an intensification of surveillance.

“In the emerging diseases worldview,” King argues, “American institutions would be both the natural leaders and the most prominent beneficiaries of the creation of a global surveillance network” (2002: 775). For instance, the CDC advanced a number of objectives aimed at securing the globe against emerging disease. According to King:

…the CDC plan […] identifies the improvement of laboratory diagnostic facilities and surveillance networks as its first two priority areas. Its stated objective is to replace ad-hoc outbreak investigation with a formal, standardized virtual network of data collection and analysis. The CDC would be the source of technology, standards and expertise, creating the computer models and risk-analysis software, furnishing regional laboratories with ‘state of the art’ diagnostics, and training foreign
personnel through a series of International Emerging Infections Programmes in developing nations (ibid. 775).

Crucial, in King’s view, is the integration of global public health with the international pharmaceutical industry. Surveillance helps to secure markets for industry by limiting demand uncertainties (ibid. 777).

Post-9/11, this orientation towards limiting uncertainty intensified (King 2003), not just in public health, but in all domains where surveillance could be extended as cold comfort against the generalizing conditions of war (for instance: Ball and Webster 2003; Lyon 2003b). As King observes, in contrast to the epidemiology of 150 years ago,

…contemporary recommendations favor a form of routinized, computerized global surveillance. This surveillance would be heavily reliant on new information technologies, databases, and molecular epidemiology, and depend on close partnerships between public health institutions, national security agencies, and private industry. Current proposals, arguing that uninterrupted global surveillance is the backbone of public health effectiveness, emphasize the unity of American national security concerns with global health (2003: 439-440 –note omitted).\textsuperscript{37}

These macro-configurations evince a global political economy and biopolitics of public health surveillance. In the words of Weir and Mykhalovskiy: “At issue here are the tactical valences of global public health surveillance in the twenty-first century, specifically whether it will serve the growth of global democracy and peace in the twenty-first century or the defense and military needs of the Global North” (2006: 257).\textsuperscript{38}

In short, the discourse of emerging infectious disease (re)configures public health surveillance for war-time deployment. Now, however, the struggle is configured less with
reference to ideological enemies, and more with reference to ontological enemies. Humanity
itself is held to be at stake, and this calls for a globalization of surveillance. At the same
time, since the enemy is microbial, this globalized surveillance also attempts a molecular-
level gaze. Already, since the 1930s, biology had come to “visualize life in terms of
phenomena at the sub-microscopic region – between $10^{-6}$ and $10^{-7}$ cm. Life, that is to say,
was molecularized” (Rose 2007: 44). As Nikolas Rose argues, this molecularization
amounted to “a reorganization of the gaze of the life sciences: their institutions, procedures,
instruments, spaces of operation, and forms of capitalization” (ibid. 44). With the
globalization of this reorganized gaze, however, the life sciences have been confronted by
the law of diminishing returns. Computerized processing power promises to overcome such
barriers but, stretched between the global and the molecular, surveillance remains, in the
words of Haggerty and Ericson, “a mile wide but only an inch deep” (2000: 618).

The visualization of molecular complexity on a global scale is a technocratic dream.
It is predicated on the mastering of information, or what Beniger evocatively describes as the
“destruction or ignoring of information in order to facilitate its processing” (1986: 15). This
dream is given sense by the crisis-driven logics that sub-tend the immaterial conception of
information. In the next section of this article I will describe how the macro-configurations
of this technocratic dream can marginalize local orders of concern. That is, I will describe
how these configurations foster a set of local exclusions and thereby circumscribe the nature
of public health surveillance.

**Marginalizing Local Orders of Concern**

It is not coincidental that, following the emergence of HIV, there was increasing concern
with fortifying global surveillance against emerging infectious disease. HIV, after all,
appeared to “attack” the cells of the immune system, making the development of a technoscientific surveillance apparatus seem the more urgent. In 1986, the same year that the International Committee on Taxonomy of Viruses (ICTV) conferred the name of HIV upon the AIDS virus, *Time* magazine described it in the following terms:

> The invader is tiny, about one sixteen-thousandth the size of the head of a pin… Scouts of the body’s immune system, large cells called macrophages, sense the presence of the diminutive foreigner and promptly alert the immune system. It begins to mobilize an array of cells that, among other things, produce antibodies to deal with the threat. Single-mindedly, the AIDS virus ignores many of the blood cells in its path, evades the rapidly advancing defenders and homes in on the master coordinator of the immune system, a helper T cell (cited in: Sontag 1977/1989: 105 -ellipsis original).

There is, of course, a long history of metaphorical tropes that figure the body as a besieged fortress. Sontag suggests that the war metaphor came into wide use, in medical discourse, after the identification of bacterial causes of disease (ibid. 66). But, with HIV, the tenor of the discourse changed. In spite of descriptions that figure viruses as simple, their “activities are far more complex than those envisaged in the earlier germ models of infection. Viruses are not simply agents of infection, contamination. They transport genetic ‘information,’ they transform cells” (ibid. 156). Hence, viral infections seem to call for an intensification of subcellular surveillance, and for the deployment of **prefficient** visualizing technologies.

In what follows, I consider Catherine Waldby’s analysis of the biomedical approach to the HIV/AIDS epidemic. Her analysis is instructive because it suggests the ways that larger political tides influence the creation of population-level knowledge about HIV/AIDS. It also suggests how surveillance practices bridge different “centers of calculation” (Latour 1999: 72), such as the laboratory and the clinic, and how these centers, in turn, reproduce
social norms. As such, it suggests how macro-configurations might characterize the way in which local orders of concern are marginalized. Nonetheless, as I will argue, Waldby’s critique also needs to be supplemented with attention to local practice. Without this focus, analysis of the macro-configuration of public health surveillance risks participating in the marginalization of local orders of concern.

Waldby’s analysis begins with a consideration of the uniqueness of the viral challenge to human identity. Viruses, she argues, can destabilize the ontological status of the human. They can do so because “viral infection involves the colonization of human genetic identity with viral genetic identity” (1996: 1). Within the logic of war, viruses “are understood to replicate themselves through their annexation of the reproductive apparatus of human tissue cells, forcing the human cells to manufacture alien viral cells, forcing human identity to participate in its own infectious defeat” (ibid: 1). According to this description, viruses present a particularly insidious challenge to human identity. Waldby argues that, within the binary oppositions established by the war context, medical scientists regard themselves as the true opponents of viruses because only they command the knowledge and technology required to fight them. The capacity to visualize a virus at the molecular level secures the scientist’s claim, she contends, to wage war. Moreover, the capacity of HIV to disable the body’s defense system, “rather than engage in honest warfare with the immune system like lesser infectious agents” (ibid. 3), makes the positioning of biomedical science as the body’s second line of defense the more urgent. To critique this development, Waldby articulates the concept of the biomedical imagination, which she defines as “biomedicine’s speculative and explanatory universe” (ibid. 5). I will suggest a critique of this concept below. First, however, let me briefly show how Waldby illuminates the totalizing tendencies of discourse dominated by a war-time, crisis thematic.
Waldby argues that biomedicine’s control strategies “do not ‘target’ the virus alone, but rather ‘target’ the person as a viral agent” (ibid. 20). This is a deeply (bio)political practice because it relies on unexamined and naturalized notions of identity in order to intervene in the epidemic. In other words, these strategies rely on superficial information that must be modeled in order to generate a picture of any depth. For example, in Ontario, persons presenting for an HIV test give, in addition to basic demographic information, information about risk-factors. These include “sex with women,” “sex with men,” “needle use (injecting drugs/steroids),” “has lived in endemic area,” “heterosexual partner of a person at risk of HIV (list exposure category of heterosexual partner),” and so on (Ontario, MHLTC, 2006a). These categories necessarily depict patients in static terms. Similarly, the screening regime makes little distinction amongst the myriad different sub-types of HIV. For instance, for the purposes of disease reporting, mandated under the province’s Health Protection and Promotion Act, a person either has a positive finding with respect to a listed disease, or does not. Hence, both patient and pathogen are pre-figured in a static, superficial way.

On the basis of such superficial information, Waldby asserts, the biomedical imagination attempts to visualize the body as though it were transparent. The illusion of transparency is achieved by allowing ideal types (superficial information) to stand in for objects. The supposition that biomedicine’s superficial information corresponds to its object, the body, “legitimates biomedicine’s power to diagnose and manipulate its objects, to undertake clinical practices like surgery and public health practices like screening which require the trust and at least tacit consent of its patients and potential patients” (Waldby 1996: 30). The difficulty, Waldby argues, is that the biomedical imagination makes things up:
“On the one hand it creates narratives and on the other it realises, or struggles to realise, these narratives through their embodiment” (ibid. 32).

This process of making things up involves judgments about what is normal, and, for that matter, what is healthy. Following Georges Canguilhem, as well as Foucault and others, Waldby asserts:

…any operative concept of health is enmeshed in and partially derived from current descriptions of pathology. This suggests to me that whatever concepts of health are dominant at a particular historical moment can be read as a negative registration of whatever forms of pathology are silent at that moment (ibid. 38).

In other words, the normal is always read against a register of the pathological. Additionally, the biomedical imagination organizes the relationship between health (the normal) and disease (the pathological) according to the prevailing social order.

Waldby writes: the “conditions of epidemic present a particularly urgent provocation to such analogies [between social order, health and disease], because in the biomedical imagination epidemic is a pathology which operates at the level of the entire social order” (ibid. 40).

The sense of crisis engendered by war-time conditions makes desirable those discursive techniques which seem to admit clear, concise communication. Perhaps no discursive technique claims more clarity than mathematical expression.

Certainly, mathematical expression founds the disciplines of virology, immunology, and epidemiology. The exemplars of each discipline are articulated with reference to populations (of viruses, of cells, and of mammals). This common foundation enables a reciprocity between each field and “means that a discovery in one [field] can be translated easily into the knowledge of the other without distortion or ‘noise’” (ibid. 98). Recall my
discussion of cybernetics literature in chapter 2. Information was immaterialized in order to solve the problem of noise in the channel. Here, Waldby is concerned that, in the biomedical imagination, the material heterogeneity of patients’ bodies is just so much noise, a problem to be filtered out by surveillance infrastructure.

Waldby’s critique of the biomedical imagination gives a reasonable picture of how ideational and institutional tendencies might marginalize (filter out) local orders of concern. Insofar as it is plugged into an overarching normative structure, the biomedical imagination is subject to the same sexist, racist, ageist, ableist – in short, biopolitical – tendencies that dominate the structure in which it is nested. These structural tendencies characterize and specify the nature of marginalization. To put the argument in blunt terms, virology, immunology, and epidemiology provide the template for reductionism while the political climate determines who (and what) will be reduced.

At this point, however, it must be acknowledged that the biomedical imagination is itself a superficial truth and does not exhaust the reality of biomedical practice. Consequently, although Waldby’s work illuminates the tendencies embedded in the globalization of war-time public health surveillance, there are myriad ways in which people deconstruct, contest, negotiate and resist such processes in practice. Indeed, to attribute too much power to the biomedical imagination would be to participate in the marginalization of local orders of concern. Just as the techniques of virology, immunology, and epidemiology have the capacity to efface local orders of concern, so too can an overly deterministic conception of the biomedical imagination efface patients, microbes, frontline practitioners, and even local, organizational heterogeneity. In fact, however, the marginalization of these local orders is systemic; it is related to crisis-driven, war-time logics desirous of controlling information.
The recent shift towards syndromic surveillance illustrates this point. As Lyle Fearnley notes, syndromic surveillance refers to the practice, developed in the 1990s, “of monitoring health databases such as ER (emergency room) triage logs, 911 (emergency) calls, and pharmaceutical sales” (2008: 1620). As an example of syndromic surveillance, Fearnley describes New York City’s ER triage system, known as the “chief complaint system”:

At the ER, patients report their “chief complaint” – their primary symptom – to the nurse, who enters it into a computer database designed to facilitate the proper distribution of patients in the hospital. The syndromic surveillance system utilizes networked connections to transfer chief-complaint data and geographic identifiers (zip code) from the ER to the health department. Ideally, this transfer takes place in real time, but more often transfers occur in what epidemiologists call ‘near real-time’: hourly or daily batches. Once inside the health department’s computers, chief complaints are automatically translated into standard syndromes: for example, ‘coughing’ becomes ‘respiratory’ (ibid. 1620).

From this description, it is apparent how such a system could be useful for public health practitioners. The difficulty with syndromic surveillance, however, lies in the attempt to automate decisions about the significance of symptoms. At what threshold does a cough become a respiratory illness? Fearnley suggests that, if this question is algorithmically answered in advance, then the role that remains for local public health practitioners is to follow-up on the signals sent by syndromic surveillance systems.

In short, as Fearnley’s incisive research indicates, the rise of syndromic surveillance suggests an inversion of the relationship between public health worker and information technology (IT). This inversion, in turn, raises the provocative question as to whether IT is a tool for public health practitioners, or whether public health practitioners are becoming tools of IT? Questions of this kind would be precluded by deterministic conceptualizations
of the biomedical imagination. For this reason, it is important to supplement critiques of the biopolitics of public health surveillance with attention to local practice.

To conclude, large-scale, IT-mediated surveillance techniques produce information by filtering out information. This is a dual process that necessarily involves both a degree of reductionism and a degree of totalization. Waldby’s concept of the biomedical imagination illustrates how such reductionism and totalization might be specified and characterized by the prevailing social order and according to crisis-driven, war-time logics. However, to the extent that it posits a rigid distinction between biomedicine and other local orders of concern, it risks excluding local practitioners from the analytic frame. As a consequence, and in order to fully grasp the systemic nature of the marginalization of local orders of concern by the war-time, crisis-driven appeal to immaterial information, it is necessary to supplement analysis of the biopolitics of public health surveillance with detailed empirical study. This area of research, however, remains under-developed and beckons the attention of surveillance studies scholars.

**Conclusion**

My goal, in this chapter, has been to provide sketches that suggest how a war-time ethos pervades the contemporary concept of public health surveillance. In the first section, I discussed the development of the US CDC Epidemic Intelligence Service. Specifically, I focused on Langmuir’s mobilization of concern about a biological weapons attack to institutionalize a cadre of disease detectives. I also suggested that this institutional foundation fostered an ideational distinction between surveillance and control, and that this distinction is now taken for granted in the contemporary concept of public health surveillance. These institutional and ideational movements evince a desire for clear
boundaries, one characteristic of the pragmatics of war-time logic and emergency-management strategies.

In the second section, I suggested that public health surveillance today is articulated less with reference to ideological enemies, and more with reference to ontological enemies. In the discourse of emerging infectious disease, “Humanity’s ancient enemies are, after all, microbes” (Garrett 1994: 10). Of course, this formulation ignores the fact that humans could not exist without ‘their’ microbes, the microbes with which they live in symbiosis (Hird 2007 and 2009). In so doing, it fosters an intensified, globalized, superficial surveillance that depends upon and promotes the pursuit of immaterial information. This surveillance is increasingly computerized and automated.

Taken together, these sketches suggest how war-time logics might marginalize local orders of concern. In the final section of this chapter, I focused on Waldby’s critique of the biomedical imagination. Her critique indicates some specific ways in which surveillance is connected to the larger normative order, thus showing how this normative order might characterize and specify the nature of marginalization experienced by local orders of concern. Specifically, it illustrates how the techniques of virology, immunology, and epidemiology can resonate with each other in a surveillant assemblage. The mathematization of each field allows for the creation of a coherent picture. However, such a picture necessarily involves reductionism. Under war-time crisis-conditions, reductionist operations are obscured, setting the stage for the marginalization of local orders of concern.

I have argued, throughout this chapter, that the concept of public health surveillance is woven of war-time mentalities. In its present ideational, institutional configuration, it produces a garment that is ill-suited to local needs. I have deliberately argued that scholars must be attentive to local orders of concern, broadening the less cumbersome, more
classically sociological, assertion that scholars must be attentive to patients. I take attention
to patient concerns for granted. My choice, however, to focus on local orders of concern, is
motivated by the belief that the marginalization of patients is bound together with a more
systemic form of marginalization, and that this, in turn, potentially forecloses alternative
ways of thinking about health and disease. This systemic form of marginalization has to do
with institutional and ideational tendencies oriented towards the immaterial conception of
information. These are tendencies to ignore material aspects of information in order to
facilitate its processing. Just as they tend to marginalize patient concerns, so, too, do they
tend to marginalize microbial concerns.

Moreover, these tendencies play upon a tension inherent in public health work. As
public health practitioners work to negotiate their dual responsibility to patients and the
collective public, the issue of the nature of this public looms. Who is this public? This
question is of a piece with another unanswered question: who are those who need to know?

Operating according to war-time logics, it would seem that those who need to know
are, increasingly, those powerful few who possess the technological capacity and know-how
necessary for plugging into global circuits of disease management. They are exemplified by
the quintessential figure of the technocrat. But this figure, too, is an ideal type. It is a
macro-configuration that is deformed by everyday practice. For this reason, an adequate
theorization of public health surveillance must be locally, empirically situated. Alexander
Langmuir himself suggested a good entry point for empirical study by including, in his
definition of surveillance, the idea that it should involve “all who have contributed”.
Although this idea was subsequently dropped, it is a thread that may now be picked up by
surveillance studies scholars interested in expanding “those who need to know” to include
those who have contributed by being surveyed.
Chapter 4: The Organizational Order of Concern

~ “No data bases have ever magically arrived chock full of numbers”

(Krieger 1992: 413).

In this chapter, I begin to (re)theorize public health surveillance by focusing on the material heterogeneity of local orders of concern. The first local order I consider is that of the local public health organization. In chapter 2, I observed that discourse that recommends investment in IT as a solution to growing medical care costs tends to overlook the labour required to make such solutions effective. Then, in chapter 3, I cautioned against analyses of the biopolitics of public health surveillance that similarly neglect the local heterogeneity of surveillance practice. In this chapter, I examine surveillance practice in relation to a single information system in a public health setting. This focus brings out the materiality of information apparent at a local-organizational level. It foregrounds the labour that constitutes the range of different information-processing practices which are necessary to both make information, and to hold it together in a useful assemblage.

Before proceeding, let me first recap my critique of the conception that information is immaterial. This conception grounds a set of problematic assumptions, which are nicely evoked by Krieger’s pithy statement, quoted above. To begin with, if I believe that information is immaterial, then I can uphold a distinction between information and its material contexts. Upholding this distinction, I can also assume that information can move, unchanged, from material context to material context. For example, if I believe that information is immaterial, then I can also believe that the information on this computer is the
same as the information on that computer. Moreover, if I believe that information is immaterial, I can also assume that the information contained in this document today will be the same information contained in it tomorrow. In sum, an immaterial conception of information elides or minimizes material differences that are extended in space and time and which contextualize information.42

This minimizing of differences in the material of information is a communicative pre-requisite. The mistake, contained in the conception that information is immaterial, is the belief that material differences are only a feature of interpretation and not inherent to information. When I assume that these differences do not exist, there is no reason to ask questions about what makes information function (what makes it appear comprehensible) from place to place, and from time to time. In short, there is no reason to think about the energy, the labour, involved in holding bodies of information together.

In this way, the labour involved in communicative work subtly disappears from view. Holding a body, or assemblage, of information together involves aligning, or canceling-out, spatial and temporal differences. A great deal of the work of communication is embedded in classifications, nomenclature, taxonomies, standards, norms, and so on. As Bowker and Star (1999) have argued, these tools enable objects to travel across boundaries while appearing to maintain a constant identity. This movement from context to context is achieved, they contend, when objects are endowed with a weak structure, and when individual actors tailor this weak structure to fit a particular context (1999: 16). In this chapter, I am concerned with the tailor-making of information, the “informal work-arounds” (ibid. 54) that enable, and sometimes disable, the constitution of bodies of information.

I explore the heterogeneity of information-processing practices both within and between organizations. To explore these differences, I rely upon 38 semi-structured
interviews with public health workers in Ontario. The interviews were wide-ranging, but here I want to concentrate on responses to questions about the use of IT in public health. During the course of these interviews, the promises and pitfalls of the new integrated Public Health Information System (iPHIS) emerged as an issue for participants. Following the SARS outbreak in Ontario, and as part of a broader response to the recommendations made by the Naylor, Walker, and Campbell reports (Canada, NAC 2003; Ontario EPS 2003 and 2004; Ontario, SARS Commission 2004 and 2006), the Ontario provincial government announced the launch of iPHIS in January 2005. This system replaced Ontario’s older Reportable Disease Information System (RDIS). It was meant to link together the province’s 36 public health units, and to help public health practitioners with the work of communicable-disease surveillance. According to an Ontario Ministry of Health report, entitled *Operation Health Protection*, iPHIS was to be fully implemented in the province by 2006 (Ontario, MHLTC 2004: 24).

In this chapter, I will highlight the different information-processing practices that frustrated the implementation of iPHIS. Before doing so, however, it will first be worthwhile to locate iPHIS amongst the broader, information environment. As I will demonstrate, the rationale underlying efforts to create a smooth-functioning set of information systems submerges the messiness of information-processing practice from view. By taking a progressively more microscopic view, the materiality and heterogeneity of the information-processing practices, practices that constitute information systems, come into view. The more information-processing practices are the focus of inquiry, the more necessary it becomes to abandon the view that IT is simply a tool that aids public health workers. Indeed, in the final section of this chapter, I will suggest that investment in IT can initiate a paradoxical transformation. The case of iPHIS indicates a core tension, in public
health work, between the imperative to collect information, and the imperative to deliver care. Moreover, as public health surveillance becomes increasingly global in focus, communicative work has an increasing capacity to displace localized, “shoe-leather” epidemiology (King 2003: 439).

**The Messiness of Material Information**

Public health surveillance is, as I have suggested, an increasingly global concern. Several notable studies have discussed global public health surveillance, especially as it relates to international law and global health governance (for instance: Baker and Fidler 2006; Bashford 2006a, 2006b; Fidler 2003, 2004, 2005; Mykhalovskiy and Weir 2006, Pisani et. al. 2003). The global view afforded by these studies is beyond the scope and intent of the present work, though global-level developments and relationships certainly play a structuring role in local public health surveillance practice. To give a sense of the context in which iPHIS is nested, I will sketch out a few contours of the broader information environment. Starting at the nation level, I descend through layers of complexity towards local levels. This sketch will suggest how difficult it would be to achieve a global-level view of the material heterogeneity of information-processing practices.

In Canada, public health surveillance is primarily a matter of provincial jurisdiction, though the federal government does lead a number of national surveillance initiatives. In 2004, following the SARS outbreak, the federal government created the Public Health Agency of Canada (PHAC) in order to “enhance surveillance by developing and implementing data collection standards” (Canada, DoF 2004). Additionally, in the same year, the federal government committed $100 million towards the development and implementation of “a high quality, real-time public health surveillance system to assist in the
timely identification of infectious disease outbreaks such as SARS” (ibid). Initiatives of this kind do impact public health surveillance at a distance; however, their impact at the local level has not yet fully played out and, in some sense, remains minimal. Hence, I will now put these national initiatives into abeyance in order to achieve a more detailed perspective of the context in which iPHIS operates.

In Ontario, local public health units are empowered by the provincial government, under the *Health Protection and Promotion Act* (HPPA), to undertake mandatory programs and services, such as communicable-disease surveillance (Ontario CRC 2005). There are also a range of provincial organizations that undertake work germane to health surveillance, for instance, The Ministry of Health and Long Term Care (MHLTC) and The Ministry of Children and Youth Services. Ontario is creating a central Agency for Health Protection and Promotion. At a regional level, there are 14 Local Health Information Networks (LHINs), and these are responsible for planning and funding health care services within their boundaries. Public health units are organizationally separate from the LHINs, but they are supposed to collaborate with LHINs on issues relating, for instance, to population health assessment, data management, emergency management and infectious disease control (Ontario CRC 2006: 49).

In addition to the government organizations that process health information, there are a number of non-governmental organizations engaged in health information processing. Examples of these organizations are Cancer Care Ontario, which maintains disease registries, the College of Nurses of Ontario, which maintains a nursing database, and the Pediatric Oncology Group of Ontario, which maintains its own Networked Information System, a database on childhood cancer cases. I will now put this list of organizations, which is
illustrative rather than exhaustive, into abeyance to achieve a still more detailed view of the context in which iPHIS operates. I will now concentrate on information systems alone.

There are numerous information systems at work in Ontario today. According to the Ministry of Health and Long Term Care, there were, as of 2006, eighty information holdings in use in the province (Ontario, MHLTC, 2006a: 1). This number excludes, the Ministry notes, database and information holdings based on current and historical health surveys (in a non-exhaustive list, the Ministry profiles over fifty of this kind of information holding in Ontario, MHLTC 2006b). In what follows, I will zoom in on a single information holding – iPHIS – with the intent of considering what holds this holding together.

Let me begin this zooming-in process with a consideration of two diagrammatic representations of information flows. The difference between these two diagrams is telling. Their juxtaposition shows how the material basis of information can be submerged from view in attempts to create large-scale systems.

In 2004, as part of a broader information management initiative, the MHLTC conducted research to identify how information is collected, where it is stored, who has access to it, who makes decisions based on it, and how it flows between databases. On the basis of this research, “a more organized, efficient, and ultimately more sustainable way of managing health information through its entire life cycle to meet the information needs of health system planners, analysts, managers and decision makers” was proposed (Ontario, MHLTC 2006c). The graphic representation of this proposal, Figure 1, discloses the desired end product, the goal towards which reforms in information management are directed.

As it is reproduced below, Figure 1 is too small to allow readers to make out the various names of the information systems depicted. I will enlarge portions of Figure 1 momentarily, making some of these names more legible. For the time-being, however, I
want to direct attention to the orderly and seemingly rational nature of these information flows.

**Figure 1: Clean Information I**

Note that most of the arrows in this diagram point from left to right. This is how information is supposed to flow. I want, now, to zoom in on the two leftmost columns of this diagram, entitled *Data Sources and Transactional Systems*. I have enlarged these columns in Figure 2 below.
In Figure 2, the phrase *Patient Identifiable Data* spans the bottom of the two columns depicted. The unidirectional arrows suggest that information ought to flow from frontline organizations like public health units, hospitals, family physicians, screening clinics, pharmacies, and so on, to information aggregators. These aggregators are transactional systems and are represented by regional-level coordinators, the MHLTC itself, disease-specific registries, and so on.

Information is supposed to be channeled through information aggregators towards the right side of the diagram. Eventually, information is supposed to be anonymized and/or pseudonymized, rendered useful for organizations that are described, in Figure 1, as information users. These organizations are conjoined, in Figure 1, by a vertical bar designated *Legislature & Public*. Figures 1 and 2 represent a desired end-point, a goal towards which to strive. They signify a response to what the MHLTC discovered when it researched information flows in 2004. Figure 3, below, offers a snap-shot of the Ministry’s 2004 findings. Here, again, the diagram is too small to read. I will enlarge portions of it momentarily in order to present them in more detail. For the time-being, however, I want to direct attention to the stark contrast between Figure 1 and Figure 3.
The story told by the juxtaposition of Figure 1 and Figure 3 is about the chaos of information processing, and the attempts of organizations to contain and clean up that chaos. In Figure 3 information flows are multi-directional, overlapping, and criss-crossing. Not only does information flow from left to right and back again, but it also leaps up and down vertical columns. Some flows, shaded grey, are designated as obsolete. Apparently, however, they are still part of the picture, and must be factored. A dotted arrow designates a flow under development, a “Possible To-Be Flow”. In Figure 3, in the central column entitled Information Holdings, there is a single column of eight blocks above a dual column.
The single column corresponds to the Ontario MHLTC’s information holdings, while the dual column corresponds to the information holdings of external partners of the Ontario MHLTC. This column can be seen more clearly in Figure 4, a magnified portion of Figure 3.

Figure 4: Messy Information II
The bottom block of the single column in Figure 4 corresponds to public health. This block can be seen more clearly in Figure 5, a magnified portion of Figure 4. In this block there are three sub-blocks, and the middle of these sub-blocks corresponds to the Reportable Disease Information System (RDIS), and to the system that replaced it, the integrated Public Health Information System (iPHIS).

Figure 5: Messy Information III

In the next section of this chapter, I open up and explore the information-processing practices within the iPHIS box. This exercise will demonstrate that the entanglement of data-flows linking the boxes, so nicely displayed in Figures 3, 4, and 5, is mirrored by a further level of entanglement that holds together the box itself. It will also show how local information flows can mirror the trajectories of more global information flows. For instance, Figures 3, 4, and 5 show a concentration of activity around Information Holdings.
Information flows towards the government’s information holdings but, Figure 3 suggests, only trickles back to frontline settings. Such a situation lends credence to the perception, expressed following the SARS outbreak, “that communications from the public health units were non-existent or sporadic” and that “much information was provided to Public Health, but little information came from Public Health” (Canada, NAC 2003: 151).

*iPHIS is/in Practice*

In what follows, I draw from my interviews with public health workers to illustrate the way that information mutates in the course of practice. Consequently, it is crucial to attend to the local, material context of information-processing practice in order to understand how this gives shape to, and complicates, public health surveillance. Before presenting these illustrations, it will first be helpful to locate my analysis in relation to *Sorting Things Out* (1999), the seminal study of classification practice by Bowker and Star.

Bowker and Star launch their study by proclaiming: “To classify is human” (1999: 1). However, in spite of the pervasiveness of classification, in spite of its constituent role in the practice of daily life, most people stand, they assert, “in formal ignorance of the social and moral order created by these invisible, potent entities” (ibid. 3). Surveying the literature, they note that anthropologists, economists, sociologists, philosophers and statisticians have all looked at classification and standardization in various ways, but few have produced useful empirical studies (ibid. 3-4). “Few,” they argue, “have looked at the creation and maintenance of complex classifications as a kind of work practice, with its attendant financial, skill, and moral dimensions” (ibid. 5).

A key site of investigation for Bowker and Star is the World Health Organization International Classification of Diseases (ICD). By striving to get a sense of the way that
practice effects classification, they find, in the various iterations of the ICD, “not a record of gradually increasing consensus, but a panoply of tangled and crisscrossing classification schemes held together by an increasingly harassed and sprawling international public health bureaucracy” (ibid. 21). Moreover, they argue that the ICD exemplifies the way that classification systems settle conflicts among “irreconcilable ontologies” (ibid. 21) by detouring around “such higher order issues” (ibid. 24).

These observations mark an excellent point of departure for the present analysis. Ontario’s iPHIS exemplifies a large-scale, IT-mediated surveillance system. As noted, it is meant to link together the province’s health units, allowing public health workers to track cases of communicable disease beyond the borders of their catchment areas, alerting them to potential outbreaks. As such, it is sprawled across the province’s diverse geographic regions, which span a range of more or less densely populated areas, as well as two time zones. Consequently, iPHIS faces a number of challenges, many of which amount to the problem of trying to reconcile irreconcilable ontologies. Discussing the ICD, Bowker and Star argue that local practice modifies classification, spawning new classifications. “The WHO attempted to control this process for the ICD,” they write, “by producing guidelines on how to modify the ICD for particular purposes. These guidelines were themselves modified locally, however, a classic problem in decentralized organizational control” (Bowker and Star 1999: 128).

The analysis provided by Bowker and Star cues me to examine my interview data for the ways in which iPHIS was locally modified. These local modifications, in turn, signal the presence of different ontologies, along with the mutation of information enacted within those ontologies. For ease of presentation, I’ll briefly consider the promises of iPHIS, before exploring, in greater detail, its pitfalls.
Promises of iPHIS

Prior to the introduction of iPHIS, Ontario public health units used the RDIS to track communicable disease. RDIS, however, had some key limitations. To begin with, although RDIS linked health units with the Ministry, it did not link health units with each other. This feature was problematic, especially for people charged with the task of contact tracing. For instance, although RDIS enabled contact tracing within catchment areas, tracing contacts outside one’s catchment area was more difficult. It had to be done via an inter-agency memo, usually sent by fax. Additionally, RDIS was not a real-time system. Public health units did periodic ‘data-dumps’, generally sending their reportable disease information to the MHLTC on a weekly basis.

The province implemented iPHIS, in part, to remedy these limitations by allowing the real-time comparison of catchment areas in the province. This comparative capacity would allow frontline workers to access more comprehensive up-to-date patient case-histories, and adjust their counselling accordingly. For instance, in the words of one public health nurse interviewed: “If I get a report on gonorrhea, but unbeknownst to me, this person actually tested HIV positive five years ago, I don’t have a hard copy in front of me, so I wouldn’t know that he was also HIV-positive. But if I go into iPHIS, I’ll see that, ah ha, this person actually tested HIV-positive five years ago in another city, then my counselling of him will be a bit different” (I 38). A number of the people that I spoke with were proponents of iPHIS, feeling that it was a considerable advance over the previous system. Still, much of the potentiality of iPHIS went unrealized because, as I will argue, iPHIS was a singular system in name only. In practice, iPHIS proved to be a multiplicity of systems, and creating a comprehensive picture of communicable disease was complicated, as it always has been, by different ways of dealing with, understanding and performing disease.
The Pitfalls of iPHIS

There are many factors that made a multiplicity out of iPHIS. The iPHIS architecture grants users different access based on their assigned role in the system. For instance, nurses would have access to the results of the laboratory diagnosis of their patients while epidemiologists would not. However, a nurse working in a sexual health clinic might only have access to the sexually transmitted infection module of iPHIS, and not the respiratory module. An epidemiologist would have access to both of these modules, but only the reporting end (and not the clinical end). Hence, although the term iPHIS suggests a single database, the database is itself multiple because of the structural differences amongst users plugged into the system. Additionally, as I will argue, there is an even more fundamental sense in which iPHIS is a multiplicity of systems. This has to do with the various ways in which iPHIS is locally modified, across space and time.

Let me begin by focusing on the different aspects of frontline public health work that made iPHIS a multiplicity of systems. Nursing work has been historically under-valued – even ‘invisible’ (Bowker and Star: 1999:229) – in medical care systems. This situation reflects broader socio-historical trends in the valuation of women’s work, as well as the specific way in which the medical profession is gendered. Noting this situation, Armstrong et. al. argue that, as technologies contain built in assumptions, IT in a medical care context can “simultaneously replicate power relations and establish new ones, with contradictory and often negative consequences for women’s work…” (2006: 2). In the first year of its operation, iPHIS exemplified the way that assumptions, built into IT, could have negative consequences for nursing work.

The promise of iPHIS was that it would enable the creation of a province-wide picture of communicable disease, in real-time. One of my interviewees, a program manager
from a southern Ontario health unit, suggested the specific way in which iPHIS aspired towards real-time. She noted:

I 22: With RDIS, you could only look at your specific area and we would only know what was going on in [our county]. So, if there was, let’s say, some kind of an outbreak on the edge of [our county] that went into another county, we had no idea of that. Only the Ministry would know, because they had access to all of RDIS, so they could see RDIS at all of the different areas.

MF: Right.

I 22: We'd only know our area. So, we could miss the fact that something happened at a church picnic, or whatever, or in a school that was on the border of our county, and not realize the total issue, like how big the actual issue was, or how many people were involved. So it’s [iPHIS] good that way, because right now, if I went in, and entered a client, and they had salmonella, I would be able to see, you know, where else salmonella had been detected, and have a better idea. So that’s a good thing.

The fact that it’s what we call quote real-time – that’s a very loosely used term – because it is supposedly real-time, those issues should be able to be spotted more quickly than they used to be in RDIS, because RDIS was not done in real-time. It was a tracking system, so we knew, at the end of the year, or when we reflected back on the past year, you could see how many cases of salmonella there were in [our county], and the Ministry could see how many cases there were in Ontario. iPHIS is supposed to show us how many we are currently investigating. Hence, real-time.

The key factor enabling iPHIS to aspire towards this timeless idea is its attempt to unite data-entry work with frontline work. For instance, as imagined by designers, public health
nurses would put information directly into iPHIS as they dealt with their clients on a case-by-case basis. This, in turn, could enable the rapid, or *real-time*, detection of outbreaks.

A public health nurse from the same southern Ontario health unit described how this labour process would work in the context of our discussion about HIV screening. I asked this nurse what kind of information would be kept in my file if I tested positive for HIV. She replied:

I 20: In your file? Meaning your file on iPHIS, or the paper file that we keep?

MF: The paper file. I guess this would be a bit different, right? If you’re managing a case you need to have a bit more comprehensive information?

I 20: Yes, and we do progress notes. For every contact that I make with you, or with your physician, I would collect progress notes. And then the same as the other things that I mentioned, your demographic information, your treatment info, sexual contacts, symptoms, reason for your testing, your physician information, risk factors… Anything that we enter into iPHIS is on a form, we actually have a form that we use to collect all of the information needed for iPHIS entry, and we don’t collect any more than that, just what’s on our form. And then we enter that exact information into the system, except for the progress notes.

While this nurse preferred iPHIS to RDIS because it gave her access to information beyond her catchment area, she noted that it also took more time to use. The program manager that I spoke with at this same health unit put this workload problem in the following terms:

I 22: Well, there is certainly more work to it than we were ever led to believe. It’s been much more time-intense, and resource-intense. […] It’s difficult because, when you put in a new program like
iPHIS, that is so involved, but you don’t take away any of the work from the people who are in the field, it’s very difficult for them to attend to the training and the learning.

Additionally, this participant observed a tension between the work of case management and data entry:

I 22: …which comes first? Obviously the case management, because you have to find out who is ill, and how they got ill, and who else might become ill, and try to break that chain of infection, right? So that’s the priority, to break the chain. Sometimes the data inputting has to be put off until the crisis is managed.

As these comments suggest, the idea of unifying frontline work with data-entry work was complicated by the fact that data entry is, indeed, work.

The under-valuation of this kind of work was built into iPHIS.\textsuperscript{45} Corroborating the experiences at this southern Ontario health unit, a manager from a different southern Ontario health unit observed that using iPHIS took roughly 4 times longer than using RDIS: “the Ministry has agreed that it takes about four times the amount of time that RDIS did. So that was kind of a surprise to everybody… not a happy one” (I 19). Recall my argument, from chapter 2, that an immaterial conception of information is bound together with propositions about the extraordinary power of IT. Such propositions elide the labour involved in making IT work. In this respect, iPHIS exemplifies not only the under-valuation of nursing work, but also the way that value systems are subtly built in to IT.

A number of factors militate against this pursuit of immaterial information. A focus on the material differences in information-processing practices highlights the difficulty involved in the creation of a uniform picture of communicable disease in the province. For
instance, as a consequence of the increased workload associated with iPHIS, a number of health units in the province continued to rely on clerks in order to manage information. This created a situation wherein some public health units in the province were relying on frontline clinical staff to enter information into iPHIS, while other public health units were relying on centralized data-entry clerks. One public health nurse I spoke with summed the issue up succinctly:

I 46: We’re coming up to release 6 of iPHIS now. That will be in the next month or so that we’ll be receiving that, and certainly public health division has created a lot of sub-committees who are looking at different aspects of the iPHIS program, best practices, and so on. I think one of the biggest challenges is, in terms of business practice, that not all health units are doing the same things. They all have different processes that make iPHIS work. So, I think that, sometimes it’s a bit more challenging if you’re working with a health unit that doesn’t do things exactly the same way that you do them.

In addition to highlighting the fact that the computer system itself changes (iPHIS had been through 5 upgrades by the time I spoke with this nurse) the above description points to the effect that “informal work-arounds” (Bowker and Star 1999: 54) have on information. It also highlights the labour involved in overcoming these challenges. As this respondent noted, “I think, certainly, that public health division is working hard to develop best practice guide-lines for how to use the system. I think that once those are up and running, and once health units are doing things the same way, it will be a really valuable system” (I 46).

My interviews indicated a rich heterogeneity of information-processing practices, not only across health units, but also within health units. The evidence suggests that this heterogeneity is effaced when labour is subsumed under an immaterial conception of
Moreover, increased data-entry workload is but one dimension of labour effaced by the immaterial conception. Another dimension is training. The training issue surfaced in various ways and indicates how difficult it can be to maintain a level of continuity, not only across public health units, but also within public health units. One doctor from a northern health unit captured a number of points related to this issue. My conversation with her went as follows:

MF: […] Actually, I have another question – I think it’s going to be more particular to the northern catchment areas that have separate offices across a large geographical terrain. Did that present any specific challenges in your region?

I 41: You’re asking if our geography has created specific challenges related to surveillance?

MF: Yes, related to surveillance, managing iPHIS…

I 41: OK – Sure, it’s a little bit of a challenge because we have one central office and [a number of] branch offices. In the branch offices, we have staff in charge of some of this reportable disease work, who are part-time staff, and who would see individual cases of different reportable diseases quite rarely. And so, it is challenging for them, to feel like they are maintaining their competence, to be able to enter data when the incidence is so low. Most computer programs you need to use to maintain your familiarity and feeling of competence with them. And so, it is challenging. We have set up, for some reportable diseases, a system where the actual data entry into iPHIS is done centrally, at our main office, to avoid data-entry that is not as standardized as we would like.

A manager from a different northern health unit gave the training issues a different spin. She noted:
I 44: …I think that they didn’t factor in the fact that there is also a lot of turnover of staff in health units. You no sooner train someone, and then someone new comes along. […] I really think that the system itself is not hard to work in, once you actually know what you’re doing and you’ve had sufficient training. I think that it will be fine to continue with that system. I think that they just need to look at doing regular training sessions to make sure that people actually know what they’re doing, and that we’re all doing it consistently.

Here, training in the use of a new system is in tension with other organizational factors. High turnover of staff exerts an influence, for instance, as does the frequency with which communicable disease occurs in a given area.

Indeed, the issue of the occurrence of disease is the elephant in the room here. As I argued in the previous chapter, communicable (infectious) disease is framed by war-time logics. Consequently, public health workers cannot help but feel a crisis-level pressure when outbreaks are perceived. In such situations, the key question is whether iPHIS will help with outbreak management. Some of the nurses I interviewed felt that iPHIS would be too cumbersome to be effective in a crisis situation. Information entry simply took too much time and effort. The tension between training to use an IT system for public health work, and public health work itself, was illustrated nowhere more clearly than in conversations I had with a nurse and a manager from a southern Ontario public health unit. In their case, iPHIS training took them out of their catchment area to an urban centre. While they were away, a communicable-disease outbreak occurred, and they had to drop training mid-way, race back to their catchment area, and attempt to control the situation. This was a clear example of iPHIS hindering, rather than helping, public health work.

To sum up what has been suggested so far, numerous factors related to information processing modified iPHIS locally. These factors, such as different spatial locations,
different levels of experience, and different disease conditions complicate the creation of a local-level picture of communicable disease, to say nothing of the provincial-level picture. There are more factors still. Frontline workers have face-to-face relationships with their patients. As such, the public health clinic bridges two sometimes divergent sets of interests. Public health workers must negotiate the occasional tension between their responsibility to patients, and their responsibility to protect the public. I will revisit this tension in the next chapter, in the context of HIV screening; now let me simply illustrate that public health workers are concerned with protecting the privacy and confidentiality of their patients. In the words of one public health nurse from southern Ontario:

I’ve been doing it [surveillance] for thirteen years, with our program, and definitely, we have refined what it is that we collect. That’s a concern, sometimes, with health surveillance. You can be collecting all kinds of data. But do you really need it? I think you have to balance a lot of that stuff off with the right to privacy, our client’s right to privacy. What gets put on computer, and how protected that is, in this day and age…[pause] with iPHIS and everything else, the area of concern that I have is, how much information is available to other people, and breaching that client’s right to privacy (I 21).

This concern effects how public health workers pre-figure what information will be entered into iPHIS. As I will illustrate in the next chapter, public health workers have some discretion in this regard.

For now, I want to underscore the fact that public health workers are not the only agents that exercise discretion with regards to information processing. Indeed, iPHIS itself is also an agent of change. In the context of a conversation about HIV/AIDS screening,
one public health doctor from a southern Ontario public health unit observed the following difficulties. She stated:

I 37: [iPHIS has] been particularly problematic in the area of HIV/AIDS, partly because they didn’t migrate all of the data fields over, and those are obviously diseases where it’s not a one time thing where a person is treated, and then cured of it. So, we’re missing a lot of the data elements. We’ve also had problems with the dates. When we receive multiple lab reports on somebody, the system is changing the dates. So that, if a person was diagnosed with HIV, say two years ago, and we receive another lab report, the date of diagnosis changes to the current lab report’s date.

MF: Oh geez. So it’s an automatically updating field?

I 37: Yes, so those kind of bumps are being fixed in the system. But, in the province, we are not able to produce reports on some of the risk factors data right now. It’s difficult. We’re able to get aggregate numbers and basic demographic information out of the system. But some of the information we used to get out of RDIS, we’re not able to get out right now.

I was especially interested to learn about how iPHIS was changing the dates of lab reports. This example suggests how the material of information itself changes. While these kinds of changes are commonly regarded as glitches, and therefore epiphenomenal, they also indicate something much deeper: information is fundamentally connected not only with the labour that motivates it to flow, but also with the material infrastructure that flows information.

Given these connections, it must be recognized that iPHIS is not simply a tool that public health workers use. Rather, iPHIS interacts with public health workers, who must, in turn, interact with iPHIS. Public health workers and iPHIS work, now together, now at odds with
each other, and this practice of work, this enacting of public health surveillance, complicates both the picture of communicable disease, and the picture of public health surveillance.

Lessons from iPHIS

All of the quotations presented above raise points that are germane to my argument about the material dimensions of information. Numerous different factors contextualize the performance of information processing. The heterogeneity of information-processing practice thus poses a challenge for public health surveillance. These challenges are not insurmountable, but neither do they tend to be accounted for in the design of IT, or in policy recommendations concerning IT, as the case of iPHIS illustrates. Arguably, then, an immaterial conception of information is responsible for this accounting flaw. I will now draw some pragmatic conclusions that follow from this accounting problem. First, the implementation of a large, inter-organizational system is an ongoing project. It would be naïve to assume that such a system could be implemented in a given span of time (such as a year). A focus on information-processing practice suggests that implementation projects are never complete. Factors internal to the system (such as software and hardware upgrades, serendipitous autonomous computer action, employee turnover, and so on) will continually change. And, factors external to the system will bring their own challenges. Weather delays holding up files as they travel from peripheral offices to central data-entry points, economic cutbacks, or a rapid increase in the incidence of disease, can all pressure surveillance systems.

There is a further important lesson to take away from the above discussion. iPHIS introduced changes into the work of public health. In some cases, it increased time spent doing information processing. In other cases, with regards to training, it took staff away from their frontline duties altogether. Additionally, iPHIS raised issues, for public health
workers, about the privacy and confidentiality of their patient’s personal health information. Although all of the people I spoke with were confident that iPHIS, and the provincial public health system in general, could keep patient information secure, iPHIS nonetheless raised questions for them about the kind of information that should be collected, and the purposes for which it should be used. Finally, iPHIS could sometimes work at odds with public health workers. For example, it challenged them with data quality issues with regards to the date of HIV laboratory diagnosis.

What do these challenges mean for public health work at the local, organizational level? In order to understand the nature of the transformation of public health by IT, it is worthwhile to consider an observation from Etheridge’s history of the US CDC. When the US entered the Second World War, it established an agency for Malaria Control in War Areas (MCWA). This agency, which subsequently became the CDC, was staffed mainly by engineers and entomologists. Their primary task was to identify malarial vectors and control these with the liberal application of chemicals, such as DDT (Etheridge 1992: 1-10). Gradually, the MCWA morphed into the CDC and, as discussed last chapter, increased funding was allocated to the development of the Epidemic Intelligence Service. As the CDC became increasingly focused on epidemiological work, there was less and less funding for engineers and entomologists. Hence, the rise of the epidemiological core of the CDC corresponded with the demise of its engineering and entomology core.

Considering this transition, one wonders whether a similar transition is taking place today. As public health becomes more concentrated on communicative work, what will happen to its epidemiological core? In discourse that views IT as a ‘mere’ tool meant to aid public health work, it can be supposed no conflict exists between IT and epidemiology. Such a supposition, I contend, is wedded to an immaterial conception of information. It
does not adequately consider information at the level of processing practice. It cannot, therefore, adequately contemplate the occurrence of such tensions.

**Conclusion**

The examples of the previous section, drawn from my interviews with public health workers, attest to the messiness of information-processing practice. Recall the diagrammatic representations of iPHIS (Figures 3, 4, and 5), discussed earlier. Figure 6, below, magnifies a portion of Figure 5. Gone, from this picture, is the chaotic tangle of information flows that bind the province’s communicable-disease surveillance system together with a much larger, more complex assemblage.

![Figure 6: 'White Boxing' iPHIS](image)

The box containing iPHIS, as well as its predecessor, blocks out yet a further chaotic tangle. By peering into this box, by glimpsing the heterogeneity of information-processing practices that constitute this information holding, a more complex picture emerges. In light of such local complexity, it seems fitting to suggest a revision of Figure 6. The box itself is subtended by a mangle, or mess, of different flows, which I have represented in Figure 7 below.

![Figure 7: Opening up the 'White Box']
Information holdings are held together by information-processing practices. When these practices are subsumed under an immaterial conception of information, they disappear from view. As I argued in chapter 2, reports that recommend investment in IT tend to assume that information is immaterial. Equally, as suggested in chapter 3, critiques of the biopolitics of public health surveillance commit a similar error to the extent that they ignore the material heterogeneity of such practices. In both cases, an immaterial conception of information, whether implicit or explicit, assumes that information signifies in the same way regardless of time or place. As a consequence of this assumption the significance of information-processing practices is minimized; the material diversity of such practices, and the effort required to unify them, is underestimated.

Moreover, with regards to Figure 7, the revisions I have made obliterate the neatness of the diagram, making the box difficult to read. Such is the effect of concentrating on the material heterogeneity of information. This concentration suggests that efforts to achieve a rationalized, ever-more globalized information system, are not without cost. Sacrifices must be made in the name of this choice.

In chapter 3, I sketched some of the historical macro-configurations of public health surveillance. I carried on with this sketching of macro-configurations in the first section of this chapter, describing the broader information environment in which iPHIS is located. I also indicated that this environment can only be sketched by ignoring a tremendous amount of information. The juxtaposition of Figures 2 and 4 suggests just what is ignored: the information flows and the labour practices that perform them. Hence, my goal was to draw out some elements of the micro-configurations that give shape to public health surveillance, as manifest in the information-processing practices that constitute iPHIS. I think that the decision to strive towards a province-wide communicable-disease system had the effect of
submerging a local order of concern from view. My intent, in claiming this, is not to argue that such a choice is necessarily bad (though I do think it had some negative consequences). Rather, my intent has been to suggest that an immaterial conception of information makes it difficult to evaluate the choice to invest in a province-wide surveillance system.

In the next chapter, I shift focus from a consideration of communicable-disease surveillance to a consideration of the surveillance of a specific communicable disease: HIV/AIDS. This focus allows me to bring into view a different set of relations that underpin communicable-disease surveillance. It also lets me argue that an immaterial conception of information submerges these relations from view.
Chapter 5: The Personal Order of Concern

In the previous chapter, I concentrated on the implementation of a system meant to facilitate the surveillance of communicable disease in the province of Ontario. By focusing on the implementation of this one system, I was able to highlight the material heterogeneity of information-processing practice. This focus enabled the suggestion that changes in IT provoke changes in public health work (and not necessarily for the better, as is commonly supposed). Paradoxically, the institutionalization of a province-wide IT system had the effect of subordinating the very local order of concern it was meant to aid. It arguably undermined the provision of public health by drawing resources and attention away from more traditional modes of public health activity, by making more work for public health professionals. In this sense, iPHIS marginalized local organizational orders of concern.

In this chapter, I look at the subordination of a different local order of concern. Taking the surveillance of HIV/AIDS as my focal point, I first note that iPHIS plays only a very marginal part in the development of a robust, population-level view of the epidemic in Ontario. Next, I examine the process of getting an HIV test in Ontario. In the third section of this chapter I suggest that patient concerns are *immaterialized* by the HIV test requisition and the broader HIV screening process. This is tantamount to a marginalization of local, personal orders of concern. In the final section of this chapter, I argue that such marginalization is related to systemic tendencies in the provincial HIV screening program.

The empirical focus of this chapter centers on a provincial epidemiological report, as well as on semi-structured interviews conducted between April 2006 and September 2007. In the first section, I briefly consider the *Report on HIV/AIDS in Ontario 2005*, published in March 2007. The second section relies upon an analysis of 29 interviews with public health
workers. These interviews are drawn out of the set of 38, which were introduced in the previous chapter.\textsuperscript{46} In the third section of this chapter, I draw on 8 semi-structured interviews, conducted between April and September 2006, with participants who have had an HIV test. The majority of participants for this set of interviews were recruited at a 2006 Opening Doors Conference. Additional participants were recruited through a community organization in Kingston, ON. In the final section of this chapter I relate my empirical data to other empirical studies that concentrate on people’s experience with the HIV test in Ontario.

My empirical data suggest that people experience a measure of exclusion during the HIV screening process. I think this presents a two-fold problem for the screening-surveillance regime. First, because surveillance relies on categorical ideal-types to stand in for patients, there is a risk that these ideal-types will misdirect public health interventions. This risk is amplified when embodied patients are excluded from surveillance processes. When patients are absent, there are simply fewer checks on the validity of the ideal-types used in screening and surveillance. Second, to the extent that surveillance processes exclude the subjects of surveillance, these processes reproduce the covert ethos of their war-time institutionalization. When persons have no input into or control over knowledge that is produced about them, they are put in a difficult position, especially when that knowledge is used to coerce or control them. Similarly, public health practitioners are put into difficult ethical and political circumstances when they must use knowledge so derived for control purposes. These difficulties stem from the marginalization of the personal order of concern, an order that is marginalized when subsumed under an immaterial conception of information.
The Epidemiology of HIV/AIDS in Ontario: iPHIS versus LAByrinth

In Ontario, the epidemiological picture of the HIV/AIDS epidemic is derived largely from an information system housed, not in public health units, but in public health laboratories. I think that this factor is noteworthy for two reasons. First, the diagnosis of a person’s HIV status is rooted, fundamentally, in the laboratory. As Catherine Waldby notes, because HIV infection is largely devoid of symptoms for a long period of time after contraction, “the HIV test carries a particularly heavy diagnostic weight, producing the only evidence that infection has taken place” (1996: 113).

Moreover, laboratory testing occupies a hinge position between clinical and public health. Waldby writes:

First it [testing] produces vital signs for the purposes of monitoring the state of the public health with regard to particular diseases. In this way increases in the incidence of, for example, cervical cancer and per-cancerous neoplasias can be measured and analysed, causes for the increase can be sought, education campaigns designed and so on. Second, testing works as the first component in an individual diagnosis for the person screened. It either provides reassurance that no hidden pathology exists, or it brings them into the ambit of clinical medical attention and demands a reordering of everyday life around a new status as […] ‘future ill’ (Waldby 1996: 116 –citation omitted).

In this sense, laboratory testing is central both to HIV/AIDS diagnosis, and to public health efforts to picture the epidemic in populations.

Second, in addition to being a central part of HIV diagnosis, laboratory testing is also, in Ontario, centralized. There are 12 public health laboratories in the province. While some regional laboratories conduct preliminary HIV screening, all confirmatory tests are performed at the province’s Central Public Health Laboratory, in Toronto. Both stages of HIV testing (preliminary and confirmatory) are logged in an information system, called
LAByrinth, that links regional laboratories with the central laboratory. The machines that perform the preliminary screening test are connected directly to LAByrinth, while the results of the confirmatory test, which is less automated, must be entered into the system manually. Compared with iPHIS, its automation of information processing and limited spatial distribution make LAByrinth a considerably more centralized system. This configuration enables the creation of a far more sophisticated population-level picture of the HIV/AIDS epidemic in the province, a picture I will now briefly discuss.

It has been estimated that there are between 48-68 thousand people living with HIV and AIDS in Canada (Canada, PHAC 2006: 2). The Ontario HIV Epidemiologic Monitoring Unit, formed in 1996 by the University of Toronto Department of Public Health and the Ontario Ministry of Health and Long-Term Care, produces in-depth reports on the evolving HIV epidemic in the province. In March 2007, the unit released its ninth annual surveillance report on the HIV epidemic in Ontario.

Up to 2005, in Ontario, there have been 26,461 HIV diagnoses and 8,233 AIDS cases reported. For the purposes of the argument that I will develop in the final section of this chapter, it is noteworthy that, between 1992 and 2005, there were over 4 million HIV tests performed in Ontario. Of these tests, 16,168 have been positive for HIV (Ontario HIV-EMU 2007: 79). For this same time period (1992-2005), 12,509 males have tested positive, compared with 2,976 females. Similarly, in every year during this same time period, the number of male AIDS cases reported has numbered in the hundreds, while the number of female AIDS cases has only exceeded 50 twice. This comparison of HIV and AIDS diagnoses, by sex, is interesting because of the 4,088,292 HIV tests performed between 1992 and 2005, far more females have been tested for HIV than males: 1,758,673 male; 2,183,653 female; and 145,966 of unknown sex (ibid. 87). While men have borne the
burden of HIV-disease in the province, women have been subject to/had access to more testing. This discrepancy is interesting from a sociological perspective, and it is a point that I will return to in the final section of the chapter. For the present, however, I want to focus on where these figures come from.

The Ontario HIV-EMU derives most of the serological information in its reports from Ontario’s voluntary HIV testing system. Most of this information is housed in the LAByrinth database (ibid. 1). Additionally, the report uses information on AIDS cases from the Ontario notifiable disease system, the system that iPHIS was designed to support. As I focused on iPHIS in some detail last chapter, it will be worthwhile to consider here what the Ontario HIV-EMU had to say about the transition from RDIS to iPHIS. The authors of the 2007 report write:

Until April 2005, AIDS data were maintained in the Ministry's Reportable Disease Information System (RDIS) which was implemented in 1990. This system provided for the organization of data on reportable diseases at the local health unit level and for electronic transfer to the Ministry of Health and Long-Term Care. In 2005, the new Integrated Public Health Information System (iPHIS) replaced RDIS. [...] To verify data quality, we compared data among cases in RDIS and iPHIS and found that some data fields in RDIS had been incompletely imported into iPHIS. No specific variables on risk factors for AIDS were yet available in iPHIS, although risk factors could be derived indirectly in some cases. Therefore, we adjusted exposure category distributions in recent years to compensate for the limited risk factor information available. Few cases in iPHIS included the dates of diagnosis of AIDS indicator diseases and the AIDS diagnosis date in iPHIS did not always match the date of diagnosis of AIDS in RDIS. [...] Due to the difficulties related to the transition to iPHIS, we used data in RDIS for this report if the case was present in both RDIS and iPHIS; these cases constituted 95% of cases in this report. 0.5% (41) of cases in this report had data only in RDIS and 4.6% (376) had data only in iPHIS (ibid. 4 –reference omitted).
That iPHIS did not contain information on risk factors, that it did not contain information on dates of diagnosis of AIDS indicator diseases, or that the dates between RDIS and iPHIS did not always match, meant that data from the public health clinic was far less stable and reliable than information from the laboratory.

It is worth underscoring this point. More than simply not helping with the creation of the province-wide epidemiological picture, iPHIS is actually confusing that picture.\textsuperscript{52} Even in 2008, when the Ontario HIV-EMU published its analysis for the year 2006, it was still relying heavily on both \textit{LAByrinth} and RDIS, a system for which information processing had been discontinued (Ontario HIV-EMU 2008). With relation to HIV/AIDS surveillance iPHIS failed Ontario on two counts. On the one hand, and as discussed last chapter, iPHIS took longer to use. To put the argument bluntly, it redirected human resources towards communicative work and away from public health work. On the other hand, this extra work did not result in information that epidemiologists could use to create a provincial epidemiological picture of HIV/AIDS. A manager-epidemiologist I spoke with gave a succinct diagnosis of the problem. He stated:

\begin{quote}
For a system that’s province-wide, there should be a lot more emphasis put on quality. The bottom line is that a lot of people just don’t realize that if you put garbage in, you’ll get garbage out. So, if you don’t spend a lot of time looking at the quality of the data going in the system, then how can you trust the case counts, or the statistics you generate (I 17)?
\end{quote}

In fact, epidemiologists at Ontario’s HIV-EMU were unable to trust the statistics generated by iPHIS. Instead, they had to rely on the much more robust information contained in \textit{LAByrinth}, and augment this information with other sources, such as RDIS. The lesson
here, I think, is that a simpler system, with fewer users and more automation, enables a
clearer epidemiological picture. However, as I will argue in the next section, such clarity is
not without cost.

An extended chain of translation – the process which links the public health clinic to
the public health laboratory – is submerged from view by LAByrinth. This is not to say that
public health workers are not aware of the chain of translation that produces the information
in LAByrinth. On the contrary, they have detailed knowledge of the process. Rather, my
argument is that, LAByrinth filters out the ‘noise’ of this aspect of the screening process. In
so doing, it operationalizes the ideational and institutional disconnection between screening
and public health surveillance. Although such a disconnection is useful for the
concentration of efforts upon the generation of a population-level view of the epidemic, it
makes certain problems difficult to consider in relation to surveillance. For instance, ought
the reconfiguration of screening be undertaken, even if this has adverse consequences for
surveillance?

A New Circulatory System

Naomi Pfeffer and Sophie Laws, studying people’s perceptions of venepuncture, have
argued that “blood’s ontological status is in endless flux” (2006: 3022). This, they contend,
has to do with the paradoxical in/visibility of blood, its apparent low value as it circulates
inside the body, and its high value as it circulates outside the body. In this section of the
chapter, I examine a corollary paradox: that of the im/materiality of the patient. Patients, I
will argue, are eclipsed by their blood sample as it circulates through different centers of
calculation. Although patients give blood in exchange for a diagnosis, the precise
configuration of the process of diagnosis excludes the patient, I suggest, paradoxically
rendering his or her concerns temporarily immaterial. This is so because diagnosis serves a
dual purpose. As noted in the previous section, the laboratory is the hinge between clinical
and public health. Hence, in addition to providing a diagnosis for patients, the laboratory is
also key for conducting the surveillance of HIV/AIDS, as demonstrated above. In this
section, drawing from interviews with public health workers, I will describe what presently
happens when a person presents for an HIV test in Ontario.

In Canada, a positive HIV diagnosis has been legally reportable in all provinces since
May 1st, 2003 (Canada, PHAC 2006: 13).53 There are three different kinds of HIV test –
nominal, non-nominal, and anonymous – though not all provinces offer all three kinds.
These different testing options correspond to different levels of patient confidentiality. A
nominal test carries a person’s name while a non-nominal test has an identifying number in
place of a name. An anonymous test is accompanied by a code that will unlock the test
result, and that the test subject alone possesses. Ontario offers all three kinds of test, but
anonymous testing is only available in some catchment areas.54

HIV status is not listed as a reportable disease in the Ontario’s public health
legislation. However, AIDS status is listed. Since the HPPA legally obliges laboratories to
report “each case of a positive laboratory finding in respect of a reportable disease”
(Ontario, HPPA: s. 29), HIV status is reported as a matter of course. Consequently,
nominal, non-nominal, and anonymous positive-test results are all reported to public health.
Testing positive for HIV entails having both a reactive preliminary test, and a reactive
confirmatory test. Both tests require that a sample of blood be drawn from a patient.55 In
Ontario, a person requesting an HIV test will go to a doctor, or to a clinic. The principles
underpinning the HIV testing process require the informed consent of the test-subject, the
provision of pre- and post-test counselling, and the assurance of privacy and confidentiality
(Jürgens 2001: 8; see also: Csete and Elliott 2007). Under these conditions, a blood sample will be drawn and sent, along with a test-requisition (Figure 8), to a public health laboratory.

Figure 8: Ontario HIV Test Requisition
The majority of HIV tests in Ontario are performed by public health personnel, in public health laboratories. However, in a few situations, public health is not initially involved, and only becomes involved in the event of a positive test result.\textsuperscript{56} This near monopoly on HIV testing enables Ontario Public Health to work towards a consistent and high standard of care across the province. Indeed, testing outside of the purview of public health does, potentially, threaten to diminish this standard. In conversation with a medical officer of health from a southern Ontario health unit, I learned of one instance where a diagnosis was very nearly delivered by Canadian Blood Services in the total absence of counselling:

I 26: […] one of the ones we picked up turned out to be a young man who went to give blood. His blood was tested and came back positive and they just sent him and us a blurb informing him of his status. And I was a bit astounded that they would just send him a note saying ‘you’re HIV positive, and you’d better go see a doctor’…

MF: No counselling, no kidding?

I 26: Fortunately we got the letter before he did, and so we were able to send one of our nurses to go and chat with him before he got the letter.

MF: Imagine getting that in the mail!

I 26: Well, I sent a really scathing letter to the Canadian Blood Services.
As this conversation suggests, there are real benefits that accompany the centralization of HIV screening. In this case, Ontario Public Health was able to ensure that the patient in question did not receive his/her diagnosis in the absence of counselling.

The above story also suggests, however, that counselling is regarded with some ambivalence by some organizations that process personal health information. I think this reflects a general tension between a clinical obligation to patients and a public health obligation to the public. Moreover, this tension is apparent in law and policy. Although counselling is one of the most important aspects of the screening process (Jürgens 2001), it is noteworthy that provincial legislation, as well as provincial guidelines produced under the auspices of this legislation, subordinate responsibility for counselling to responsibility for testing and reporting. This is not to say that the guidelines do not stipulate responsibility for counselling - they certainly do (see: Ontario, MHLTC 1997: 44). However, the legislation and associated guidelines are far more concerned with treatment, management and testing, as well as situations of non-compliance. This orientation is not reflected, however, in the daily practices of public health workers, especially those working on the frontline, face-to-face with patients. Indeed, their concern for the enforcement of public health protection measures is tempered with concerns that directly relate to their patient’s well-being.

As the following scenario suggests, although public health workers are required by policies and law to collect certain information for reporting, contact-tracing, and epidemiological purposes, they are also concerned to leave space for their patients to negotiate these requirements. A person presenting for an HIV test at a sexual health clinic, to take an example from southern Ontario, will generally be asked for certain personal information, such as name, date of birth, and health card number. The person may or may not decide to provide this information, and, in the words of one nurse, “if they don’t want to
provide it, that’s fine, we go rolling on ahead with it” (I 22). Of utmost concern here is the patient’s knowledge of her/his HIV status, not the recording of accurate identifying information. Additionally, the above scenario is suggestive of the heterogeneity of different practices that can unfold in the spaces between law, policy, and action. These spaces permeate the testing process.

An HIV test involves the drawing of a blood sample, the filling out of a test requisition, and the subsequent journey of this hybrid package through many hands. As the extra-corporeal blood makes its way from body to laboratory, a number of different spaces of negotiation are opened up. The material of the blood, the blood itself, becomes a kind of material-information, coursing through the public health system. A public health nurse from a northern Ontario catchment area gave the following description of this process:

I 46: You’ve gone to the doctor and they do the counselling, and from my perspective, the doctor should tell the person what will happen to their personal health information, should they test positive. Usually that is covered. The specimen will go for laboratory testing. If it does test positive, the laboratory will notify the physician. But also, under the Health Protection and Promotion Act, because HIV is the agent that causes AIDS, it’s also reportable to the public health units.

So the lab result will come to the health unit. It comes in a confidential envelope and is received by the HIV program here, which is part of our STI program. It’s received by a public health nurse. That report contains the name of the patient, usually, their gender, their date of birth, their health card number. It would also include any previous testing that had been done, on that individual, if previous testing had been done. It would include the result. It would tell you the specimen number, the tests that were performed on it, and the results of those tests.
We get that piece of paper. It’s received, like I said, by the public health nurse. She stamps it and it goes directly to our iPHIS office assistant. What that office assistant does is she goes into the iPHIS program and she enters the client’s information, creating the record in iPHIS, if it’s not already there. [...] what the public health nurse would do then is contact the physician who initially ordered the testing. The nurse would ask them if they’ve received a copy of a positive result.

MF: OK, sometimes they haven’t?

I 46: It could be that they haven’t gotten to it yet. I’m not quite sure about exactly how they receive their results. But, from our end, certainly, we follow-up with the physician first. The physician would potentially give us more personal health information. For example, if the laboratory requisition is missing information that we need, then certainly the physician would advise us about that information. Then we would ask the physician how they want to approach follow-up with the client or patient.

MF: OK, so whether public health would counsel, or whether the physician would counsel?

I 46: Absolutely. And who would do contact tracing related to that individual, and all of that kind of thing.

The above discussion gives a good depiction of what happens when a person gets an HIV test. The blood sample circulates through the public health system. It travels, in some cases, across the vastness of the province, by courier to the laboratory. Tests are performed and the laboratory communicates with public health units and physicians. Physicians and frontline public health workers discuss the case and determine how best to manage it, whether the appropriate counselling and reference services have been provided, and who will undertake contact tracing and partner notification. The space of negotiation between patient
and public health worker is now supplemented by other spaces of negotiation between laboratory and public health, and between public health and primary physician.

Anonymous testing gives the above process a somewhat different character. As noted above, it is possible to get an anonymous test in Ontario. In areas where anonymous tests are performed, getting the test might unfold in the following manner, according to a medical officer of health from a southern Ontario health unit. She described the process in the following terms:

I 26: You would come into the health unit. You would say ‘I want to be tested for HIV’. You would have pre-test counselling, and you would not have to give your name. You would be assigned a number, and you would have a test, and you would be required to have that number for the results. You would come back, you would give the number to the staff who arranged for the testing, and they would sit down and give you the result in person and do post-test counselling.

MF: OK.

I 26: And as far as that goes, they would urge you to provide nominal information with regards to yourself and your contacts. But, that is not required. So, if you went through the anonymous testing program, there would be no nominal identifiable information. The statistics, with regards to the number of positives and so on, would be collected for the testing program, but there would be no identifiable information.

Similarly, a public health doctor from a different southern Ontario catchment area gave the following description of the anonymous testing process:

I 37: […] if somebody comes in and requests an HIV test, we would first explain the difference between anonymous testing and nominal testing. And so, if they chose to have a nominal test, we
would refer them elsewhere. And if they wanted to continue with anonymous testing, there is a whole pre-test counselling protocol that we would follow. And that's set out by the Ministry of Health, so it's not something that we've developed on our own. So we would go through the counselling, and then the person would have their test done. They're given a piece of paper with a code, that only they have access to, so if they lose that, they can't access their results. They cannot access them by phone. They have to come back in person, with that card. And then they would be given their results, and again counseled appropriately, based on whether their results were negative or positive. There is some epidemiologic information that is collected. So, age, gender, different types of risk factors, and ethnicity, I think, as well.

In these cases, both clinics and labs report anonymous HIV-positive tests to public health, but there is not identifying information associated with these reports.

However, anonymous testing is not available in all catchment areas. As a medical officer of health from a smaller southern Ontario health unit observed, “total anonymous screening was taking too much time and effort and we did not have enough resources for it” (I 10). Hence, and although anonymous testing centers are becoming more widely dispersed throughout the province, lack of local access meant that patients seeking such tests had to travel. In this vein, another medical officer of health, this time from a northern health unit, remarked:

I 30: [...] this is very commonly the case – [the most urban centre in our catchment area] is a blue-collar environment, and doesn’t offer an environment that is, may I say, friendly or sympathetic to people of alternative lifestyle, particularly people with a diagnosis of HIV/AIDS – most people go to other jurisdictions.

While anonymous tests account for a minority of tests performed in Ontario, they are nonetheless an important mode of intervention. The rationale for them is to provide access
to testing for people who would otherwise choose not to be tested. As with nominal and non-nominal testing, anonymous testing involves a number of spaces of negotiation into which different people enter, be they patient, public health worker, physician, or laboratory technologist. However, with anonymous testing, the patient chooses whether or not to connect with the diagnosis. This creates a problem for public health reporting, as is currently required under the HPPA.

Under Ontario's HPPA, both physicians and laboratories are legally obligated to report findings with relation to listed communicable diseases, including AIDS. However, and in the words of one southern Ontario medical officer of health, although “physicians are legally required to report [they] are notoriously poor at doing so” (I 34). She observed:

I 34: They have a variety of reasons for not reporting. One of them is, they say 'oh, the lab will do it'. And, if there has been a lab test, yes, the lab will report it. But I think there are issues there around communication and working to change physician behaviour around reporting, so that they can understand the importance of reporting. I think that's part of it. People don't really understand why they are reporting. Like, they just think it's a bureaucratic, paperwork thing. […] They don't understand what we do with it.

In addition to viewing reporting as a “paperwork thing”, physicians might be liable to under-report because of perceived tensions between public health and personal health.

If the laboratory occupies a hinge position between clinical and public health, then so, too, does the public health physician. My conversation, with the doctor just quoted, moved from a discussion of physician under-reporting, to a discussion of the tensions inherent in this hinge position. She described it in the following terms:
I 34: […] we have a focus on both the individual and on the whole population at the same time. Usually the [primary care] doctor’s focus is just on the individual. […] I think, in public health, we’re always struggling to find the balance between individual rights and the protection of public health. What measures can be taken that are minimally prescriptive for an individual yet protect the public’s health? That’s the way we work on these kinds of things. We have some very wide ranging powers, but it’s very, very rare that we use them.

Another medical officer of health, this time from northern Ontario, described the tension similarly:

I 30: We live in a society that is purely Kantian, you know, recognizing autonomy, and the principles of beneficence, non-malfeasance, justice, and what have you. Public health is based on a utilitarian philosophy which will place the rights of the individual on a second level, compared to the rights of the community at large. That is the dilemma in public health. We function, on a daily basis, recognizing the Kantian philosophy of recognition of self, of autonomy, but we don’t operate on that basis in public health. This results, often, in conflict. […] I have a patient who I have under section 22. She’s a little bit psychologically unstable. She’s actually Canadian, born and raised, but not in Ontario. She has very resistant tuberculosis. Because of the attitude we have in Canada, you can do anything you want, and there’s no respect for authority anymore. She doesn’t follow her promises, maintain herself under isolation. We can treat her as an out-patient, but she did not respect the agreement that we had. We had to then throw a section 22 under the HPPA. We put her in isolation by force. It’s very hard for people who practice public health, because sometimes you are basically baby-sitting. So, now you go into the paternalistic aspect… and [sighs]…

Public health physicians, as these quotations suggest, are sometimes in the difficult position of having to arbitrate amongst individual and communal interests. This, I think, is a reason why primary care physicians may under-report to public health. Having built up a rapport with their patients, they may be reluctant to report if they perceive some negative outcome
for their patients. Laboratories do not have direct contact with patients in the same way that frontline workers and physicians do, and this may make them more instrumental reporting centers.

With regards to HIV/AIDS surveillance, the reporting relationship between public health and the laboratory is far more developed than is the reporting relationship between public health and physicians. As one public health doctor from northern Ontario put it, “the [laboratory reporting] system is ancient. But that said, Martin, the labs fulfill their responsibility – it is a strong link, right now. That is our best source of information. The link with other health care providers is much, much weaker” (I 41). This doctor went on to suggest that, rather than working to build reporting relationships beyond the laboratory, public health might be best served by concentrating on the relationships that are already strong.

Let me sum up what is suggested by the above excerpts from my interview data. First, having an HIV test involves much more than simply giving blood. It involves depositing this blood in an elaborate extra-corporeal circulatory system. There are three different kinds of test available in Ontario, each corresponding to different levels of anonymity. These different options accord potential patients a measure of control over their diagnosis. Nonetheless, once a blood sample is given, a range of activities are triggered. Several spaces of negotiation concerning the status of the sample are opened up. It is noteworthy, I think, that, by and large, these spaces of negotiation exclude patients. To be certain, these spaces of negotiation involve deliberation over highly technical matters: who will initiate contact tracing – physician or public health; was the test requisition filled out accurately; is there more demographic or risk factor information that will aid in the interpretation of the blood sample? At the same time, however, this exclusion also relates to
the difficult hinge position that public health officials must occupy. Delivering a devastating diagnosis to a person is one thing. Having to take action that might impinge upon that person’s freedom is something else altogether. The exclusion built into the testing and screening process thus provides a measure of insulation, for public health practitioners, from patients. In this insulated space, difficult decisions can be made. Although this insulation must be necessary for people tasked with making such difficult decisions, there is a subtle risk inherent in the systemic exclusion of patients from the diagnostic process. It is to a consideration of this risk that I now turn.

A Measure of Marginalization – Experiencing the Test

The growing pervasiveness of communications IT has, paradoxically, created societies in which bodies appear to disappear. The radio broadcast, the telephone, and now voice over internet protocol (VOIP), have, each in their own way and by facilitating communication at a distance, made bodies appear somehow less material. Modern surveillance, as Lyon has argued, developed as a structural response to this condition (2001: 16). When bodies are immaterialized, when they are subsumed under an immaterial conception of information, they admit an equivalence with each other, and a statistical manipulation that is eminently useful for governance. These bodies can be compared with those bodies, and it becomes possible to think about a higher-order concept: population.

The population is a model built out of information, a manageable system “standing in for the unruly or opaque” (Sismondo 1999: 248). William Bogard has made the provocative argument that, with the advent of modern statistics, and with the reconceptualization of the real as a degree of likelihood or probability, models have become the structuring force of reality, more real than the real. “Virtual realities are the order today,” (Bogard 2006: 60), he
states, in the sense that they pre-structure fields of intervention. Bogard’s argument directs attention to the feedback loops between models and the fields of intervention that they structure.

In epidemiology, populations must often be taken-for-granted in order to get on with the work of analyzing collective phenomena (the same can be said of sociology). Geoffrey Rose’s now classic article, “Sick Individuals and Sick Populations,” distinguishes between a population approach and an individual approach to epidemiology. The individual approach, he forcefully argues, confines attention to within-population comparisons. For instance, “individuals with ‘normal blood pressure’ are those who do not stand out from their local contemporaries; and so on. What is common is all right, we presume” (Rose 1985: 32). However, he continues:

[…] the individual-centred approach leads to the use of relative-risk as the basic representation of aetiological force: that is, ‘the risk in exposed individuals relative to risk in non-exposed individuals’. Unfortunately, this approach to the search for causes, and the measuring of their potency, has to assume a heterogeneity of exposure within the study population. If everyone smoked 20 cigarettes a day, then clinical, case-control and cohort studies alike would lead us to conclude that lung cancer was a genetic disease; and in one sense that would be true, since if everyone is exposed to the necessary agent, the distribution of cases is wholly determined by individual susceptibility (ibid. 32).

The population approach, in contrast, seeks to discover whether or not there is “a mass influence acting on the population as a whole” (ibid. 34). This approach makes it necessary “to study characteristics of populations, not characteristics of individuals” (ibid. 34). While this approach has been an extremely powerful and useful way of approaching health
problems, if the strong distinction between individual and population becomes reified, the feedback loops with which Bogard was concerned become invisible.

This invisibility is apparent in the conceptual distinction made between screening and surveillance. Rose himself associates screening with the individual approach to health: “screening is used to detect certain individuals who hitherto thought they were well but who must now understand that they are in effect patients” (ibid. 35). Surveillance, in a public health context, tends to be associated with the monitoring of anonymized information, information that has been disconnected from personal identifiers.

While this is a useful pragmatic distinction, I think that it has engendered, in public health, a marginalization of patient concerns with respect to the experience of screening. For patients, the distinction between screening and surveillance may not be meaningful at all. As Scott Burris argues, for most people, the experience of public health surveillance is bound up, in various complex ways, with other concerns about testing, partner-notification, discrimination, stigmatization and criminalization. For instance, he argues that informing “a person that there is very little chance of surveillance information being released and causing harm is much like telling a person afraid of flying that planes rarely crash. The risk assessment is driven by the horror of the consequences, not their likelihood” (Burris 2000: S122). Consequently, many “people will not distinguish different parts of the ‘system,’ and so may not see the helpful public health official as distinct from the threatening legislator or policeman. [People tie] surveillance to other issues and concerns, like racism or homophobia or social rejection” (ibid. S122).

In this section, I want to concentrate on conversations I had with persons who have had an HIV test. Specifically, I asked my interview participants whether they felt they had control over the testing situation, and whether they knew where their blood, as well as their
personal information, was being sent. The people I interviewed were tested at different times, and in different places in Ontario. Although I only interviewed a small number of people who had had the experience of being tested (n = 8), and while my findings are not meant to be generalized, the interviews excerpted below suggest two things. First, by and large, participants felt that they did not have control over their situation while being screened for HIV, though those tested more recently felt they did have more control.60 Second, regardless of the level of control they felt they had, none of my interview participants knew what happened after their blood sample was taken. They just had to await the result. For a short, but sometimes seemingly interminable period, patients had to endure the experience of being noise. They were largely filtered out of the equation so that public health could make sense of their blood sample. These two findings are suggestive of areas for future research. For patients, the testing process is, largely, a black box.

I interviewed two people who had been tested for HIV under circumstances that completely excluded them. Both had awful experiences. For Samuel, tested in the mid-1980s, it felt as if he had no control over his situation whatsoever:

MF: Did you feel, in that setting, or settings, if you got tested a few times, that you had control over the situation, that you had control over your health information?

Samuel: Back then, no. No control whatsoever. Back then it was a wasting disease, so nobody expected you to live anyway.

MF: OK. Do you know, at that point, what happened? Somebody presumably took a sample, like a blood sample. Do you know where that went?

Samuel: No.
MF: They didn’t inform you?

Samuel: They just said that it was going to go the lab to be tested.

MF: OK, did they tell you what sort of tests were performed?

Samuel: No.

MF: No, so you had no information?

Samuel: Not back then (April 2006)

In a similar way, Desmond, who was tested in 1996, felt scared and alone throughout his testing experience.

MF: Well, we’re talking today because you’ve probably had an experience being tested. And, I guess, the personal question is, can you tell me about what that experience was like for you?

Desmond: Scary, very scary.

MF: Yes?

Desmond: Because at the time there was no information out at all.

MF: When was that?

Desmond: That would have been just about 10 years ago now.
MF: OK, so there wasn't very much support around?

Desmond: No, not in the area I'm in – I'm out in a rural area. I was in [place], and there was just absolutely nothing.

MF: Geez… so it was an isolating experience too?

Desmond: Very.

MF: OK… I think you’ve kind of answered this question in a way, but did you feel like you had control in that situation?

Desmond: No, not at all (September 2006).

These experiences reflect a time when a great deal of uncertainty still surrounded the testing techniques and technology, as well as how a positive diagnosis would signify in broader social contexts (Jürgens 2001: 7).

More recent experiences with testing illustrate that, although testing techniques and technology became more refined, and although the administration of the test improved, a measure of exclusion persisted. Don, tested in 2001, noted his satisfaction with the way the medical care and public health systems handle his personal information: “It’s kept very confidential, very confidential, so I’ve got nothing to worry about like that at all. I don’t have any worries whatsoever. I’m very pleased about the way that is” (April 2006). What bothered Don, however, was the interstitial space between the time when he gave his blood sample, and the time his test results were returned. Asked whether or not he felt he had control over the testing situation, Don stated:
Well, the only thing that bothered me, more than anything, was when, after the test, I knew there was going to be two weeks, before I could find out. And I went home. And it was the worst two weeks of my life, because I was laying there, in my apartment alone. [...] I ended up being in the apartment for two weeks. And I felt that I had the plague. I felt like, ‘Can I touch something?’, ‘Are they going to have to sterilize the apartment?’, or, you know? It was a terrible, terrible, terrible two weeks (April 2006).

The psychological stresses associated with testing are widely recognized (Jürgens 2001: 77). As Don’s moving statement makes plain, such stresses – especially in the period between giving blood and getting results – can be intense.

Over time, as the HIV/AIDS epidemic has evolved in Ontario, the situation has improved. My conversation with Sally and Angela illustrates this improvement. Sally, tested in 1999, had a very different experience from Angela, who had been tested ten years earlier. The contrasting experiences they reported illustrate how radically the testing process has improved:

MF: I’m trying to get at people’s experiences getting tested. Can you tell me about how that was? What kind of support was there?

Angela: That’s easy. There was no support for me. That was in 1989. I was told that I had AIDS, first of all, when I was HIV positive. And she referred me to a supposed specialist in HIV, which took my blood a month after my first diagnosis.

MF: A month!
Angela: A month after my first diagnosis. And he took my blood, and after a few weeks I went back, and he couldn’t even read my chart! So then I just gave up on everything. And then, eventually, a year after that, I went to an AIDS project and then we got, you know, counselling and all kinds of stuff came along. But it was not through health services, or anything of the sort, or hospitals, or doctors – nothing!

[---]

Sally: See, I was in a better situation. I had a doctor that diagnosed me, kind of took my arm, and he said right there, we’re giving you an HIV test, and that was that. But, he also had two patients before me that were HIV positive. I kind of lucked out and got some good support from my doctor.

MF: He or she had some experience?

Sally: Yes – he runs the [place] men’s clinic… he’s… he’s awesome.

MF: OK, so if I can draw a contrast between your two experiences, would you [Sally] say that you felt like you had control over that situation, and would you [Angela] say that you felt like you didn’t have control over that situation?

Angela: Yes, I didn’t whatsoever.

Sally: Yes, see, I had more control. But then, also, Angela was tested 10 years before I was, so the situation has changed somewhat. But, still, there’s people getting diagnosed right now that don’t have that support system. I just happen to be really lucky with the support that I had. Because I was tested in [place], and I got all my information like that. They sat down with me and talked with me for an hour and a half. They supplied information and led me in the right direction, where I could get all kinds of help. So, I was fortunate there, I guess. I lucked out.
MF: Another more particular question, and I think it sounds like it’s going to be different responses for each of you again, but, did you know, basically, what happened, like what the test was? Did people tell you, like ‘OK, we’re taking your blood and we’re going to test it for HIV?’

Sally: Oh – definitely…

Angela: Yes… I was well aware…

MF: Did you know where your blood was sent? Did they tell you that?

Angela: No.

MF: You [Sally] neither?

Sally: He just referred me to the hospital, to the clinic at the [place] General Hospital (April 2006).

As this exchange suggests, patients have been progressively more involved in their diagnosis. And yet, there remains a level of exclusion in the sense that none of the people I interviewed knew about the nature of the test performed, or about exactly where their health information and blood sample went after it was extracted from their bodies. The laboratory and public health system remains, as these exchanges suggest, a black-box. The question of the consequences of this exclusion remains. Does it matter? Is such exclusion simply a necessary facet of modern medical diagnosis? Would greater patient involvement in this process be desirable? These are questions for future empirical research, but I want to briefly address them in the next section.
Linking Screening and Surveillance

Laboratories play a central role in the medical care and public health system. Sometimes they act as a “first-line testing facility when a novel agent emerges,” and “at other times as a reference centre or ‘court of last resort’ to standardize and improve testing procedures...” (Canada, NAC 2003: 113). They are also “a key resource in infectious disease diagnosis, surveillance, and epidemic response” (ibid. 113).

However, at the same time that laboratories were increasingly playing a central role in the delivery of medical care and public health services, social scientists were becoming increasingly worried about how laboratory diagnosis was standardizing people’s ailments, apparently turning individual experiences “into bureaucratic gobbledygook” (Illich 1976: 41). Counting laboratory diagnosis as part of a broader, “intense medicalization” (ibid. 78) of life, Ivan Illich famously argued that such interventions reduce a person’s capacity for self-determination by requiring “submission to the authority of specialized personnel” (ibid. 96). Following a similar line of argument, Dorothy Nelkin and Laurence Tancredi express concern over the growing acceptance of diagnostic technology as the pre-eminent mode of identifying disease. Such pre-eminence fosters the assumption, they argue, that a diagnostic test “is a more legitimate sign of disease than self-reported symptoms and therefore can be used to anticipate the presence of disease in the absence of overt manifestations” (1989: 39).

On the one hand, the laboratory occupies a central role in clinical diagnosis and medical practice. On the other hand, as presently configured, laboratory-based screening and surveillance involves a measure of patient exclusion. The juxtaposition of LAByrinth and iPHIS tells a story about the trade-off between patient involvement and surveillance accuracy. LAByrinth captures a set of translations meant to turn blood into information for clinical diagnosis and provincial-level epidemiology. It reduces the complexity of diagnosis
down to a few key variables. Additionally, compared to iPHIS, it is more centralized, automated and has fewer users. Where surveillance is concerned it seems that *LAByrinth*, an older and much less expensive IT system, is a much better provincial-level epidemiological tool than is iPHIS. However, iPHIS seemed to promise a measure of proximity to patients that *LAByrinth* does not. It was an attempt to move data collection closer to the frontline, closer to the clinic. Ostensibly, the information collected for iPHIS has more to do with the social determinants of HIV-disease than its biological markers. It is significant that iPHIS, as an attempt to capture a wider stream of more up-to-date information, proved so problematic for provincial-level epidemiology. Indeed the juxtaposition of these systems indicates the material reality of the trade-off between scaled-up surveillance, on the one hand and, on the other hand, a more comprehensive diagnosis of HIV-disease.

*LAByrinth*, which provides the bulk of the information for the provincial-level epidemiological picture, achieves clarity by virtue of its distance from clinical concerns. Its information is much more superficial, but also much more coherent. At least, it is much more coherent in one sense. To the extent that HIV-disease can be comprehended as a viral disease, then this picture is coherent. Additionally, to the extent that HIV-disease can be comprehended as a viral disease that effects some populations more than others, based on different risk profiles for those populations, then this picture is coherent. However, just beyond the frame of this coherent picture are the messy, virtual feedback loops that connect surveillance to the ‘thing’ observed.

At this point, I would like to relate my earlier observations, drawn from conversations with people who had experienced the HIV test, to research on prenatal HIV testing in Ontario. In making this connection, I want to highlight the fact that the exclusion of test subjects from the testing processes promotes a reification of the risk profiles of these
subjects. As these risk profiles stand in for patients, they recursively (mis)direct surveillance, leading to the sub-optimal configuration of the screening/surveillance regime.

Recall my observation from the first section of this chapter. I noted that, in Ontario, women have been subject to/had access to far more HIV testing than men, in spite of the fact that men have borne the greater burden of HIV-disease. There are a number of reasons for this. To begin with, it is related to the history of the HIV/AIDS epidemic in North America, and can be seen as a way of compensating for past wrongs. At the outset of the epidemic in North America, it was widely believed that women were somehow biologically less susceptible to HIV, owing to the supposed “rugged” nature of the vagina. Today, women are understood to be more biologically susceptible to HIV (WHO 2008b). Consequently, on this line of reasoning, women should get more screening than men.

Additionally, the routine HIV screening of pregnant women is widely advocated. In Ontario, as a matter of course, pregnant women are tested for syphilis and hepatitis B. Additionally, they may “opt-in” for an HIV test. In 2005, an estimated 86% of pregnant women opted-in for the HIV test (Remis et. al. 2006). There are, undoubtedly, good reasons for testing women at this juncture. It appears to make sense from a resource allocation perspective as there is already a well-developed clinical infrastructure for prenatal care. Furthermore, if a pregnant woman tests positive, intervention (antiretroviral treatment) can be taken to prevent HIV-transmission to the fetus.

However, there is a sense in which testing at this juncture comes too late for pregnant women. A 2002 study that interviewed pregnant women about their experiences with the provincial prenatal HIV testing program observed the following view among participants:
[...] many women were very clear that pregnancy was not the most appropriate time to raise the issue of HIV infection with women or to offer testing. Preconception, before deciding on pregnancy, at the time of an annual pap smear or physical examination, for example, were favoured by many women for the offer of HIV testing as knowledge of their HIV status would have been a factor in their decision to become pregnant (Leonard et. al. 2002: 71).

Other perspectives in this study included the view that women should have access to the test early enough to be able to decide whether to terminate the pregnancy. Additionally, it was noted that “the offer to test for HIV should be carried out over several visits allowing for personal reflection and discussion with the woman’s family and partner as appropriate” (ibid. 71). These comments are indicative of the fact that medical infrastructure is concentrated around gestation and birth (as opposed to, say, conception). Where is the obligation for partners to be tested prior to conception? While surveillance using LAByринth can identify viral, behavioral and demographic causes of HIV-disease, there are many more causal elements that it does not picture. Excluded, for instance, are the multiplicity of different performances of identity amongst populations, as these are performed in the context of their multiple social relations. In this sense, to concentrate screening on “women” is to underestimate both the bluntness of the picture created by surveillance, and the material force of this picture in the creation of women as biologically susceptible to HIV.

Unfortunately, the circular relationship between the increased screening of women, and recommendations that women be increasingly screened, makes it easy to lose sight of the crucial feedback loops that cause surveillance to occupy a hinge position with relation to problems. Surveillance helps to identify problems but, in doing so, it also constitutes problems. Just as the laboratory occupies a hinge position between clinical medicine and public health, and just as public health physicians occupy a hinge position between care and
control, so too does surveillance occupy a hinge position between the identification of
disease and the conceptualization of disease as a problem for certain sub-populations.

Let me now draw the different strands of this chapter together and argue why it is
problematic that patients experience a measure of exclusion in the HIV screening process.
To begin with, the IT-mediated surveillance system that works best for provincial-level
epidemiology is rooted in the laboratory rather than the clinic. This arrangement gives
frontline workers some distance from the diagnosis, among other things. It produces a
cleaner, ostensibly more objective provincial-level epidemiological picture. However, the
cost of this clarity is the exclusion of a multiplicity of material factors, one of which is the
embodied patient. I heard from patients about their experiences of exclusion. I was
interested to learn that, while the people I spoke with generally felt well-cared for by the
medical care and public health systems, and while the HIV screening process seems to have
improved over time, a measure of exclusion persists. Clarity is created by the exclusion, or
minimization of some kinds of information, in this case information in the form of
embodied patients.

I think that an immaterial conception of information facilitates the construction of
this clarity. Here information abstracted from patients stands in for the material
heterogeneity of patients. It then becomes possible to direct surveillance towards a class of
patient, women for example. At the same time that the materiality of patients is
immaterialized in order to make them a class, the class itself exerts a material force, directing
systemic surveillance to some places and not others. While patients remain on the margins
of screening and surveillance, the substitution of a class for a patient can proceed apace.

Here is the crux of the matter: to what extent is large-scale, IT-mediated HIV/AIDS
surveillance misdirected by its concentration on classes of people? The issue is less about
the danger of diagnostic technologies supplanting patient experience, though this is a concern, and more about the problem of technologies “making people up” (Hacking 1986) in an insufficiently nuanced way.

Conclusion

My intent, in this chapter, has been to home in on the way that large-scale, IT-mediated HIV/AIDS surveillance can marginalize a key local order of concern: patients. To begin with, it is noteworthy that iPHIS proved a less than useful system with regards to generating the epidemiological picture of HIV/AIDS in Ontario. As illustrated in the first section, the \textit{LAByrinth} system, the laboratory-based system for sero-surveillance, generated a much more coherent picture of the epidemic in the province.

The difficulty with \textit{LAByrinth}, however, is that it collects only a minimal amount of information germane to the spread of HIV. In the second section of this chapter I described the process of getting a blood test. As the provincial HIV test requisition (Figure 8) illustrates, the kind of information important to the provincial screening program relates to demographic details and certain risk characteristics. This form acts, itself, as a testing technology by creaming off information from the clinic in order to facilitate the operations of the laboratory. It stands in, along with a blood sample, for the patient. As the public health system works to determine the HIV status of the patient, several spaces of negotiation are opened up while the patient is \textit{in absentia}. This process effectively \textit{immaterialize}s patients, thus marginalizing this personal local order of concern.

In the third section of this chapter, I concentrated on people’s experience with the HIV test. Drawing from my interview data, I argued that patients presently endure a measure of exclusion during the screening process.
In the final section of this chapter I related my interview data to work about screening in prenatal clinics. I think there is a relationship between the exclusion of patients from the screening process and the ideational/institutional disconnect between screening and surveillance. To the extent that public health surveillance is conceived of as a separate process, the configuration of the screening regime is likely to reify already existing social divisions, such as those between “women” and “men”. The fact that medical care and public health infrastructure makes “women” more available to screening and surveillance than “men” needs to be interrogated. This line of inquiry, a project for future research, must raise questions as to whether or not screening and surveillance are adequately configured to respond to challenges posed by HIV. As a prelude to this analysis, I turn, in the next chapter, to a consideration of whether the screening procedures themselves are adequate to the challenges posed by HIV.
Chapter 6: The Microbial Order of Concern

In the previous chapter, I noted that laboratory screening brings a measure of clarity to the surveillance of HIV/AIDS, as well as a measure of certainty to HIV diagnosis. However, in this chapter I suggest that laboratories can also inject a measure of obfuscation and uncertainty into attempts to picture HIV in bodies and in populations. To illustrate how such uncertainty and obfuscation might arise, let me relate part of a conversation I had with a medical doctor associated with a teaching hospital. The story that follows illustrates the point that, even in systems with built in fail-safes, mistakes can happen:

I 49: I teach this story to my medical students every year. It’s my ‘Grinch Who Stole Christmas’ story. I had a young woman who was expecting a baby, who tested HIV positive. The obstetrician called me up and said, ‘we’re following your advice, we’re testing all of our women. This woman had no reason to be screened, other than she was pregnant. We screened her, and she was positive. Do I need to tell her before Christmas, or should I wait?’ And I said, ‘no, no we have to tell her. You know, if she’s having unprotected sex with her husband, or whoever, and then if that person gets HIV down the road, you won’t, in good conscience, be able to say it was fair to wait even a couple of days.’

This was around December 22nd, and she went the obstetrician’s office, and then came to see me in the emergency department. We counseled her about safer sex, saying we’ll work it out, saying ‘we’ve got treatments for you, we’ve got treatments to make sure that your baby doesn’t get infected. Even though it’s a bad thing to have, today, we’ve got very good treatments’, and so on.

She kept saying that it was impossible, and we kept saying that you catch HIV in the same way that you get pregnant, it’s through unprotected sex. Every pregnant woman should be screened, and sometimes the ones who end up positive had no idea that they were positive.
And then we did some more tests. We didn’t repeat her HIV test, which was positive in both tests, and the third test, which is confirmatory. We did the vial-load test, the test that shows how much virus is there, and that test was negative. We then went on to repeat all of the tests, including her screening antibody tests, and all of those were negative. So, this hopefully happens extremely rarely, but it’s happened to me once.

MF: Wow!

I 49: Our only explanation was that the blood was mixed up, and that at some level, something was mis-labeled, because the blood that was submitted under her name to the central public health lab clearly was HIV positive. She, clearly, was not.

This story illustrates that, even in a system where multiple tests determine a person’s HIV status, a measure of uncertainty can persist. These kinds of uncertainties occur at the level of everyday practice. They have to be resolved through a process of on-going dialogue between public health professionals and are a key reason why the cleaned up ideal of unidirectional data-flows will never be realized.

In this chapter though, I argue that a further, profound uncertainty subtends the uncertainty that is produced in the course of everyday practice. This profound uncertainty is not merely a product of inadequate understanding, nor of cumulative mistakes in the accretion of knowledge (though these certainly play a part). Rather, I contend that profound uncertainty is an ontological property of the world. Put simply, it is not only that people are uncertain about the world that they live in, but also that this world is itself uncertain. The world is uncertain because it exists in duration; it is not pre-determined but rather an unfolding, evolutionary process. To characterize this process as profound uncertainty is not to say that knowledge cannot exist, or that predictions can never come true. The point is
more subtle – beneath every prediction, beneath every morsel of knowledge is an evolving material foundation and, therefore, the possibility that knowledge, no matter how complete, and predictions, no matter how well grounded, will cease to obtain. Here I make a limited version of this argument in relation to the scientifically characterized properties of HIV. In this chapter, I consider these properties as they relate to HIV screening technology.

The argument is speculative, and my intent is to open a line of questioning that connects the routine practices of HIV screening and surveillance with the present impasse in the attempt to develop a cure for HIV-disease. Specifically, HIV/AIDS screening and surveillance is configured, as I have argued in the previous chapter, in a particular way. This configuration produces a province-wide, population-level view of HIV/AIDS. It concentrates on some populations (for instance, women) more than others, and it relies upon a minimal kind of information concerning sero-status and risk behaviours. Even as this configuration produces a coherent picture of HIV in bodies and in populations, it forecloses other pictures that might be essential to the development of a cure. Hence, the line of questioning I open up has to do with the limits of screening and surveillance as presently configured.

To pursue this line of inquiry, I first consider the relationship between surveillance-screening and concretization. I then discuss the concept of the virus, considering how these once fluid infectious materials came to be ascribed a set of concrete forms. This leads me to a presentation of the form of HIV, which I draw out of virology and immunology texts. Next, I concentrate on information from interviews with public health laboratory technologists, laboratory scientists, and infectious disease specialists. Specifically, I draw from a set of 8 interviews that took place between August 2006 and January 2008. In the final section of the chapter, I consider how laboratory testing techniques might superimpose a static form
on the dynamic matter of HIV, thus submerging the liveliness of the virus from view. This process is another way in which material heterogeneity is flattened out by an immaterial conception of information. Now, however, it is the microbe – HIV itself – that is immaterialized. I conclude this chapter by wondering whether this rendering of the virus might be related to the on-going failure to devise more effective ways of treating HIV-disease.

**Screening-Surveillance and Concretization**

Surveillance is a way of dealing with uncertainty. Paradoxically though, surveillance also produces uncertainty. Putting Ulrich Beck’s provocative hypothesis about risk consciousness to work in another context, it can be argued that surveillance generates invisible futures. It makes “that which is by nature beyond perception […] the unproblematic element of personal thought perception and experience” (1986/1992: 72). For example, surveillance communicates dis-ease about communicable, or infectious disease. In this way, and as Joost Van Loon argues, anxiety over newly emerging infectious disease must be seen as a product of both an increase in the frequency and diversity of epidemic disease, and, owing to developments in surveillance, a heightened awareness of epidemic disease (Van Loon 2002: 129-130). In sum, this very heightened awareness paradoxically produces a kind of ontological uncertainty about infectious disease.

Moreover, technologies of disease surveillance act as “technologies of (in)security” (Aas et al. 2008). They are part of a broader, security-oriented project that, because of its ambivalent outcomes, produce insecurity even as it strives for security. Daniel Neyland, discussing the transformation of “mundane objects” into matters of concern, specifies how the production of (in)security might unfold. Borrowing from Neyland, the first thing to
observe is the network that is built up around disease. Networks draw together “various entities in relationships of risk, threat and responsibility […]”, those relationships are to reorient the activities of the organisation around the object in focus […] and this establishes the transformed ontology of the object in focus” (Neyland 2008:29-30). In this transformation, the object in focus is paradoxically concretized, becoming a new matter of concern. In turn, such paradoxical concretization actually increases ontological uncertainty by producing both a false sense of security and the inevitable rupture of this security. In the context of this dissertation, the creation of this kind of uncertainty follows, for instance, from a commitment to identify people as HIV-positive, in the context where it is not possible to offer those identified with a cure.

Surveillance-screening for HIV, as discussed in the previous chapter, involves an assemblage of blood, people and machines. The goal is to transform “the body into pure information, such that it can be rendered more mobile and comparable” (Haggerty and Ericson 2000: 613). The “pure information” produced by surveillance is roundly believed to be immaterial, and therefore easily comparable. Under an immaterial conception, it can be assumed that one molecule of a certain size, shape, and chemical composition is the same as any other molecule of comparable size, shape and chemical composition. Moreover, immaterial information is supposed to correspond to the molecule in question, in an exact way, regardless of where or when this information is produced.

Consider the following linear sketch of the history of HIV. In the mid-1980s, HIV was identified as the causative agent of AIDS. Scientists began to accumulate information about HIV, building up an ever more complex picture of the virus, as well as its modes of transmission. Sites of intervention were identified. Risk-behaviours were targeted in order
to prevent person-to-person transmission. Drugs were developed in order to frustrate the
viral adhesion and replication processes.

In this short historical sketch, it has already become possible to take HIV for
granted. Following Latour, I can assert that, in this sketch, HIV functions as a *black box*
(Latour 1987: 2), a simple sign that designates something far too complex to be
communicated in a single paragraph. I think that the black boxing of HIV has been
premature. Moreover, I think the present configuration of surveillance, which requires that
HIV be black boxed, has foreclosed certain ways of thinking about HIV, ways that might be
beneficial, even necessary, for the development of a cure.

In what follows, I will suggest that surveillance-screening practices, designed to
discern HIV in bodies and in populations, superimpose a homogenous *form* onto HIV, thus
suppressing the *material* heterogeneity of the virus. This position is counterintuitive, and will
require some argument, especially in light of the fact that one of the goals of HIV screening-
surveillance is to track the development and spread of the virus over time. I will suggest,
however, that what is tracked are viral forms (or states), and not the dynamic virus that
appears to be at work *in vivo*. To make this claim, I need to open up two black boxes, for it
is not only HIV that has been black boxed, but also viruses more generally. What, then, is a
virus? And, what is HIV? I will address these questions below.

*Concretizing contagium vivum fluidum: What is a virus?*

Located at the threshold of life, the virus possesses a sublime quality. It inspires both awe
and terror. As a “not-quite-alive-yet-not-entirely-dead substance” (Radetsky 1991: 4), the
virus occupies a liminal space between life and death, and a point of indistinction between
self and other. According to an introductory textbook in virology, the “fundamental
characteristic of viruses is their absolute dependence on a living host for reproduction: they are obligate parasites” (Flint et. al. 2004: 12). An introductory microbiology textbook describes viruses as infectious agents. Their “distinctiveness resides in their simple, acellular organization and pattern of reproduction. A complete virus particle or viron consists of one or more molecules of DNA or RNA [but not both DNA and RNA] enclosed in a coat of protein…” (Prescott et. al. 2005: 363). These descriptions characterize viruses in terms that set them apart from cells, from other microbes like bacteria, and in terms that focus on their molecular organization and reproductive modes. They also concentrate on the relationship between viruses and infectious disease, describing them as parasites or agents of infection.

To these characteristics must be added one further crucial fact. To humans, viruses are tiny – extremely tiny. They are nothing that can be “seen” in the conventional sense of the word. Indeed, the majority of viruses are smaller than the wave-length of visible light, and therefore cannot even be seen using a conventional light microscope.64 The present-day view of viruses unfolds out of a history of seeking the cause of disease in the sub-visual world.65 During the mid 19th and early 20th centuries, the study of the relationship between micro-organisms and disease burgeoned, and many bacterial causes of disease were identified (Ackernecht 1959/1982: 175-185). However, while more and more diseases were associated with bacterial causes, there remained diseases for which no responsible bacteria could be identified.

A number of different articulations of disease causation competed amidst this swirl of discovery and frustration. The most enduring of these have certainly been Koch’s postulates, developed between 1882 and 1890. Koch’s research, first on anthrax and then on tuberculosis, led him to the conclusion that three postulates must be satisfied in order to assert that an organism causes disease. In 1882, with respect to tuberculosis, Koch wrote:
From the simultaneous occurrence of tuberculous disorders and bacilli, one cannot conclude that they are causally related. However, the existence of such a relation is very likely given that the bacilli occur predominantly where tuberculous processes are incipient or progressing, and that they disappear where the disease has come to a standstill. To prove that tuberculosis is caused by the invasion of bacilli, and that it is a parasitic disease primarily caused by the growth and multiplication of bacilli, it is necessary to isolate the bacilli from the body, to grow them in pure culture until they are freed from every disease product of the animal organism, and, by introducing isolated bacilli into animals, to reproduce the same morbid condition that is known to follow from inoculation with spontaneously developed tuberculous material (Koch 1882/1987: 87).

Three of the famous postulates can be distilled from this quotation: 1) the specific organism must be demonstrated in all cases of the disease; 2) the specific organism does not occur in other diseases or nonpathogenically; and 3) after being isolated and grown in pure culture, the specific organism must produce the disease when inoculated into healthy, susceptible animals (see, for instance: Hughes 1977: 12; Carter 1987: xviii).

However, as K. Codell Carter has incisively observed, although Koch seems to have regarded the third postulate as the most important in his publications on tuberculosis, he was unable to satisfy it in future work. He began to move away from the second and third postulates in later work, on cholera for instance, and focused instead on demonstrating the first postulate. After 1890, he never mentioned the second or third postulates as criteria for establishing causality (Carter 1987: xviii-xix).

Today, it is widely accepted that viruses cannot be cultured in a pure state on an artificial medium. They do not reproduce on their own, and can only be cultured in cell-lines, biomaterial substrates grown specifically for such purposes. No such technology
existed at the turn of the 20th century (Landecker 2007), and researchers could only speculate on the nature of organisms that they could not visualize.

One of these researchers was Martinus Beijerinck, a microbiologist from the Netherlands. In 1885, Beijerinck was asked by his colleague, Adolf Mayer, to attempt to isolate the microorganism that caused Tobacco Mosaic Disease (TMD). His efforts proved inconclusive, but he returned to the problem again in 1897, and this time he demonstrated that the juice of diseased plants remained infectious, even after being passed through a porcelain filter that retained all visible micro-organisms (Kluyver 1940/1983: 118-119). The results of this work seemed to mean, for Beijerinck, that the infectious material was not a bacterium, but instead, some other material in a “dissolved state” (ibid. 119). He published a paper on this work in 1898, entitled *Ueber ein Contagium vivum fluidum als Ursache der Fleckenkrankheit der Tabaksblätter* (ibid. 172).

Beijerinck then set aside his work on TMD while he pursued other interests. However, reflecting on the significance of this *contagium vivum fluidum* in a 1913 lecture, he argued:

> The existence of these contagia proves that the concept of life – if one considers metabolism and proliferation as its essential characters – is not inseparably linked up with that of structure; the criteria of life, as we find it in its most primitive form, are also compatible with the fluid states (Beijerinck, cited in Kluyver 1940/1983: 120).

It is important to recall this historic moment in microbiology because it speaks to a time before viruses were concretized. Prior to advances in microscopy, such as the advent of the electron microscope, debates persisted as to whether viruses were particulate or not. As Kenneth Smith (1959) reports, Beijerinck’s idea was still being quoted as late as 1932, when
the work of Wendell Stanley changed everything. Working at the Pasteur Institute in France, Stanley managed to obtain crystals of the substance that constitutes Tobacco Mosaic Virus (TMV). As ever more concentration was given to elucidating the structure of viruses, they seemed to become less and less fluid, more and more concrete entities.

The Concretization of TMV

“Both what counts as knowledge and what we mean by knowing depend,” Evelyn Fox Keller teaches, “on the kinds of data we are able to acquire, on the ways in which those data are gathered, and on the forms in which they are represented” (Fox Keller 2003: 199). Her discussion of the microscopy techniques that enabled scientists to see beyond cell membranes reveals a trade-off (not unlike the trade-off, discussed in the previous chapter, between the number of people entering data in a surveillance system, and that system’s capacity to generate a clear epidemiological picture). The price paid for “new powers of resolution, now extending all the way down to the molecular level, was the suspension of all biological activity” (ibid. 217 –note omitted). Accordingly, the trick to achieving new powers of resolution lay not only in the nature of the technological instruments used, but also in the preparation of specimen. To make the protein structures of viruses visible, scientists had to transform them into a crystalline form.

In his 1946 Nobel Lecture, Wendell Stanley describes in detail the processes he used in order to obtain crystals of Tobacco Mosaic Virus. Turkish tobacco plants were first inoculated with virus preparation by rubbing them with a gauze pad. After 2-4 weeks, the plants were then cut, frozen, and then ground. The resulting pulp was thawed and the juice was pressed out. Then, the juice was chemically adjusted to a more or less neutral pH and filtered through a ½ inch thick celite filter on a Büchner funnel. After more chemical
adjustment (to keep the pH level near neutral) and more filtering, a relatively colourless liquid was obtained. A further precipitation with salt was performed, and the precipitate was then dissolved in water. The solution was then adjusted to about pH 4, which caused the precipitation of the protein, and the protein was then filtered out. The protein was then crystallized by slowly stirring in ammonium sulfate and glacial acetic acid. Crystals could then be observed with a microscope at a magnification of 400 times (Stanley 1946/1964: 141-145).

Before Stanley, TMV was a fluid substance. After Stanley, TMV phase-shifted into solid-state form. The point underscored by the juxtaposition of Beijerinck’s *contagium vivum fluidum* and Stanley’s crystalline TMV is that the network in which the virus is actualized plays a determining role in the kind of virus that is produced. Note, here, what is determined: the *kind* of virus. I am not arguing that Stanley’s socio-technical network constructed or created the TMV from scratch; rather, Stanley’s socio-technical network actualized TMV of a certain kind and, in so doing, foreclosed other kinds (Beijerinck’s kind) of TMV.

*The Concretization of HIV*

The historical concretization of TMV points my analysis of HIV towards an examination of the historical conditions of its emergence. The story of HIV literally begins in 1987. Although the AIDS virus is decades old, and perhaps even centuries old, it did not become HIV until 1987. That was the year that the Retrovirus Study Group, working under the auspice of the *International Committee on the Taxonomy of Viruses* (ICTV) proposed – after a year of canvassing the international scientific community – that the infectious agent be designated *Human Immunodeficiency Virus* (Varmus 1989: 9). This development, which was paralleled by a
common declaration by American and French presidents Regan and Chirac, ended an
crimonious dispute between a French and an American laboratory. In the midst of the
AIDS epidemic, two scientific teams claimed priority for having discovered the causative
agent of AIDS. One team, the American team led by Robert Gallo, claimed that it had
isolated another strain of a previously discovered virus: Human T-Cell Leukemia Virus III
(HTLV III). The other team, the French team led by Luc Montagner, claimed that it had
isolated a new virus, a virus they named the Lymphadenopathy Associated Virus (LAV).
HIV was the compromise.

The dispute between Gallo and Montagner has been chronicled in detail elsewhere
(see, for instance: Grmek 1990; Crewdson 2002). What is of interest here is the relationship
between the material properties of the virus and the struggle to arrive at an agreed upon
name. As Harold Varmus, former chair of the ICTV Retrovirus Study Group, has noted,
the way that biologists have traditionally defined animal species is based on the ability to
mate productively. He writes:

Since viruses do not have sex in the conventional sense, the grouping of viruses that are so closely
related as to be accorded a common name has often been based upon any conveniently measured
biological or biochemical property, such as virus shape, or immune reactivity, or the presence of a
certain enzyme in the virus particle (Varmus 1989: 5).

Retroviruses are particularly problematic for nomenclature and taxonomic schemes.
Although they are united in the way they reverse “the usual flow of information”, they are
“manifestly diverse” (ibid. 5; Bowker and Star 1999: 90-98). For this reason, the traditional
approach to naming them has been to associate them with their host species and the
pathological reaction they produce. This approach to naming captures the virus in a
relational sense, naming it by way of implication in the relations it has with host and disease, rather than *in any direct sense*.

As I will argue in the next section of this chapter, HIV screening-surveillance technologies reproduce this oblique approach to the virus. They identify human responses to viral protein, and not the virus *in any direct sense*. This approach – to look for viral markers, but not the virus itself – is only reasonable (and indeed is only possible) if HIV can be taken for granted. Prior to 1987, HIV was an unruly group of different entities produced in different laboratories. The 1987 settlement smoothes over this heterogeneity, and testing technologies, which are globalized, take a generalized HIV for granted. With each settlement, the “modalities,” or qualifications, as Bowker and Star (1999: 78-79) and others have noted, get deleted. With the deletion of these qualifications, there is a corresponding convergence upon information considered to be relevant for diagnosing and treating HIV-disease. This convergence forecloses avenues in which alternative approaches might be developed (ibid. 82).

**Screening-Surveillance Technology: The Form of HIV**

In the previous chapter I concentrated on part of the socio-technical assemblage involved in transforming a patient’s blood sample into information for diagnostic and surveillance purposes. Here I will add to that consideration by concentrating on the HIV screening tests themselves. Before doing so, however, it will be helpful to say a few words about the discourse of immunity, and the basic scientific understanding of HIV as it interacts with the cells of the immune system.

Human immunity has been the subject of a considerable amount of social scientific interest, especially when it has been depicted in terms of a system that protects the
essentialized self from attack by foreign and apparently nefarious microbes (for instance, Haraway 1991; Martin 1990 and 1994). While there are several metaphors that describe the functioning of human immunity, it has been commonplace to view it as a system of protection “against constant attacks from both the external and internal environments” (Burmester et. al. 1998/2003: 1). A person’s immune system can be characterized in terms of specific and non-specific immunity. A person’s skin, her or his unbroken epidermis, is an example of a mechanism of non-specific immunity, while white blood cells, which can produce particular antibodies (self) to particular antigens (other) are an example of specific immunity (ibid: 1).

The cells of the immune system originate from stem cells in the bone marrow. Over the course of their developmental cycle, cells that have been derived from stem cells can become many different kinds of cells, performing many different biological functions. Where immunity is concerned, it is argued that “the most important cells […] are the lymphocytes” (ibid. 2), a kind of non–oxygen-carrying blood cell. Lymphocytes respond to antigens, molecules or substances that are ‘foreign’, like the protein of a virus particle (Fan et. al. 1989/1994: 30). There are two types of lymphocytes: B-lymphocytes and T-lymphocytes. B-lymphocytes secrete proteins, called antibodies, into the blood system. T-lymphocytes carry their antibodies on their surface. There are two types of T-lymphocytes. These have classically been described as Killer-Ts and Helper-Ts. Killer-Ts bind directly to cells carrying antigens. Once bound, they induce apoptosis in the infected cell. Helper-Ts act as signals to the other lymphocytes, interacting with B-lymphocytes and Killer-Ts (ibid. 30). The T-lymphocytes each have characteristic proteins on their surface. Killer-Ts have CD8 protein while Helper-Ts have CD4 protein. Tests have been devised to detect these different proteins, and they can be used to identify and count these different cells (ibid. 30).
HIV virus particles travel from body to body in blood or other bodily fluids, such as semen. Once inside a person's blood system, they appear to preferentially bind to CD4 protein and nearby chemokine receptors on immune system cell walls. Having bound to the cell wall, HIV is then absorbed into the cell. The enzyme reverse transcriptase, which HIV makes once inside the host cell, helps the virus to propagate by making viral DNA from viral RNA (Fan et. al. 1989/1994: 62). When the viral DNA is synthesized, it moves into the nucleus of the cell and is integrated into the host's chromosomes. At this point in the life-cycle of HIV, the reproductive machinery of the host cell produces copies of viral RNA. Some of this RNA moves into the cytoplasm of the cell and is used to make viral proteins. Some becomes the genetic material for new virus particles by combining with the newly made viral proteins and then leaving the cell (ibid. 62).

As virus particles enter the body, they elicit an immune response. Among other things, a person's body will begin to produce antibodies specific to HIV. These antibodies are protein structures that bind to virus particles or virus infected cells and mark them for further immune response. In the period immediately following exposure to HIV, there is a lag period during which viral nucleic acid and proteins are detectable, but during which no host antibodies have yet been produced (Iweala 2004: 142). From a diagnostic perspective, this creates a window-period during which time tests may not identify people who have contracted HIV.

Given what is known about the virology and immunology of HIV, there are a number of different methods for identifying the presence of HIV. These can be broken down into two kinds: those that identify antibodies to HIV, and those that identify the component proteins of HIV itself. As examples of the antibody tests, Gerald Corbitt (1999: 24) has identified Enzyme Immunoassays (EIA), which shall be discussed in more detail
momentarily, as well as particle agglutination assays, haemagglutination assays, latex agglutination assays and solid phase immunoassays. As examples of tests that detect viral proteins, Corbitt (1999: 25) cites immunoblotting tests (such as the Western Blot), immunofluorescence assays, virus neutralization, obtaining the virus in culture, and polymerase chain reaction.

_Laboratory Diagnosis in Ontario_

In the province of Ontario, as noted above, the majority of HIV tests are performed in a public health laboratory. Testing unfolds in a two-step manner. First, patient serum is screened for HIV antibodies using an Enzyme Immunoassay (EIA) (Ontario HIV-EMU 2007: 1-2). This test is generally performed twice, and if a sample has a reactive result, a further confirmatory test is performed. However, even before the tests are performed, a complicated intake process stages the blood sample for testing. Drawing from an interview with a participant from Ontario’s Central Public Health Laboratory, this staging process is described as follows:

I 55: …with any sample, the first thing that would happen is, when it’s received in the laboratory it is accompanied by a requisition. So, you have a requisition and a tube of blood. The first thing that has to happen is to make sure that that requisition and that tube of blood are actually matching. Does that tube belong to that person whose name is on the requisition. Now, if it’s nominal, then it’s a name and a name. In fact, these days, you have to have two specific identifiers, so you would have to have a name, and probably an accession number or a date of birth. So, you’re checking to be sure that it’s John Smith, born on such and such a date, and that the requisition says the same thing.

MF: Right.
I 55: The other thing you have to check for is that you know where it came from. Does it have a doctor’s name and address. Tests have to be ordered by medical doctors, or those who are authorized to order tests. So, there is a list of health professionals who can order tests. But, you have to know who did order it. Then you have to check to make sure that the sample is suitable for testing, so that it’s not hemolyzed, or broken, or that there’s enough blood in there to actually do something with. And, then, they would assign the sample and the requisition a number – it’s called an accessioning number – and then that sample would be separated from the requisition. It goes into the data entry area, and all the information from the requisition is entered into the computer system, as well as the test that was ordered. So, if it’s just HIV, then it just gets HIV. But if it was HIV and syphilis and something else, then that notation is made in the system, and a piece of it ends up getting sent into another section. But the HIV testing would always be done first.

MF: OK.

I 55: So, in the data entry process, they put in a lot of information about the sample. This includes whether it’s a whole blood sample, or separated serum. That’s actually an important point. Do you understand the difference?

MF: So, the serum is basically what you want for the test, right?

I 55: Right, but it means someone else has manipulated the sample, so, if it’s a serum sample, it’s not really the sample of choice, because there are things that can happen to specimens in other laboratories that could contaminate them, and cause problems with the result. So they record, quite specifically, whether it’s the whole blood, or serum sample. They record information about birthdate, all of the demographics for the individual, including exposure category and any symptoms that they might have. All of that is carefully evaluated by the computer system to determine how much testing to do on a sample, should it be negative. If a sample is positive, it automatically reflexes to more and more testing, to confirm that positivity, but in some cases, negative samples will get
additional testing as well. In these cases, if they could potentially be early seroconversions, or there is some reason to suspect that the person really does have HIV, in spite of the negative test results.

MF: So, if someone is in the window period?

I 55: Correct, they would go on and do additional tests.

MF: And _Labryinth_ would alert you to that?

I 55: Yes, it alerts us to that, because if you put in there that the person is at risk, and they have symptoms that are compatible with acute HIV infection, the system picks it up. It will flag it so that you can’t send out a negative report without doing additional testing. At this point of data entry, the other thing that happens is that there is a search to see if this person has been tested before. Now, if its nominal, it’s pretty straightforward. They’re looking for a match. […] There are, as you know, non-nominal tests, and anonymous tests. In the case of anonymous tests, we ask the submitter to tell us the previous anonymous test number, if they have it. This is one of the bits of information that we use for looking at testing patterns across the province, for looking at risk activity, and also looking for seroconversion rates, looking at the epidemic in as fine a detail as it can be looked at.

MF: Right.

I 55: So then, once that data entry is done, the samples go into the lab. They get separated from their whole blood tube, if they were in a whole blood tube. Or they get transferred into a special tube that the lab uses. And there are all kinds of bells and whistles in place to make sure that that is done appropriately, because that’s an opportunity for error, right, if you are moving a sample from one tube into another. You could, potentially misplace it, but there are a number of protective operations to reduce the risk of that happening to practically zero. […] And then once a certain number of tests are done each day, then they start to be reported. There are all kinds of procedures that you go through before you can actually report them, like looking for the ones that need additional testing,
which includes this reflexing thing on negatives, and then, of course, all positives. And then there is a check to be sure that, if you are testing a sample from an individual that’s been tested before, that the two results are actually compatible. So, if you had a positive on someone two weeks ago, and now you’re testing a sample that appears to be negative, the system would flag you on that too, and say ‘you can’t report this because there is something funny going on here’.

There are several notable features that merit highlighting in the above passage. First, while the laboratory operates as a site of simplification, there is a measure of complexity even in the intake process. Laboratory workers need to take care of a tremendous amount of detail, some of which has to do with the state of the blood sample, some of which has to do with what they are being told by LAByrinth, and some of which involves negotiation and consultation with other professionals, both within and beyond the lab. The testing process has been refined to a very high degree, but there is still room for error to occur on the margins of this process (for instance, in the mis-labeling of a file, or in the contamination of serum during processing at a different laboratory).

The management of this complexity requires highly trained, highly skilled labour. While laboratories continue to grow in import for clinical and public health, this human resources issue can sometimes be eclipsed, especially when it is subsumed under the immaterial conception of information. The people I interviewed felt, largely, as though they were on the margins of most discourse on public health, hidden away by the walls and benches of the lab. There was a sentiment that clinical practitioners did not fully understand what was involved in the testing process. An argument could be made, here, about an immaterialization of this local order of concern, eclipsed by the serology requisition, the testing technology, and the LAByrinth database. Indeed, as the province moves to replace LAByrinth with a new system, this issue will become the more germane.
However, for the present, my interest is with a different local order of concern. Note, in the above exchange, the role of the information system in the adjudication of the test result. It interacts with laboratory workers, flagging them to samples that potentially need more testing. On the one hand, it does so according to a pre-defined algorithm that relies, among other things, on the risk categories of the HIV test requisition, discussed in the previous chapter. This effectively automates an aspect of the screening process, organizing the screening-surveillance regime according to an immaterial conception of information. On the other hand, laboratory workers negotiate with the system. They read the “bells and whistles” of the system. This suggests that, using current technology, even the laboratory diagnosis is not a cut and dried affair. In the next two sub-sections I will focus on the screening and confirmatory tests that are commonly used in Ontario. This focus will highlight the challenge posed to the testing procedures by HIV itself, and set up the question of whether the screening regime is of sufficient depth for an adequate response to HIV.

*The EIA*

There are many different kinds of enzyme-linked immunoassay (EIA); it is a test that can be used to screen for many different kinds of pathogen. The simplest kinds of EIA for HIV use a solid surface coated with HIV viral proteins. Early test kits used whole virus from lysed cells, but, as Corbitt notes, proteins recovered in this way were highly variable and were often contaminated with non-viral proteins, from mitochondria, for instance (Corbitt 1999: 25-27). This meant that early EIAs had higher rates of false positivity than EIAs in use today. With the advent of synthetic antigens, and synthetic peptides that mimic HIV antigenic protein, it became possible to make tests without relying on virus from lysed cells.
Today, the test kits used in Ontario are produced by the American company Abbott Laboratories. A doctor and virological consultant I interviewed described the EIA procedure in the following terms. He stated:

I 54: …an EIA, or enzyme immunoassay, is a method which can be used to pick up antibodies to many different viruses. But specifically for HIV, this is done on what are called micro-well plates. Lining these little plastic wells, the manufacturer puts proteins from HIV-1 and HIV-2. So, they are coated, on the inside. One takes the patient’s blood sample, separates out the serum, and then puts that into this little well. If the person’s blood contains antibodies against the HIV virus proteins, those antibodies will stick to the surface of the well – they’ll bind because they’re specific. You wash off all of the excess serum. Now you add in a second antibody, which is an anti-human antibody. At the end of this second anti-body, there is an enzyme […] that’s why this test is called an enzyme immunoassay. So, if the first antibody didn’t stick, these antihuman antibodies have nothing to stick to. So, you wash off the excess again. These are usually animal antibodies, directed against human antibodies. This is part of the kit, or the test.

MF: What sorts – I mean, would they be from a mouse?

I 54: Usually mouse antibodies, but they can be goat, or other species, rabbit, for instance.

MF: That’s owing to genetic similarity?

I 54: No, it has nothing to do with that. What you do to get these antibodies is, in your little mouse, you inject the mouse with human antibodies, so that the mouse makes anti-human antibodies. So then they’ve got this little enzyme at the end. The final step is adding in a substrate to break down or react with. When it does that, you get a colour reaction, and the thing will turn yellow or blue. You then, using an instrument, shine a light through here [through the micro-well] with a receiver at the other end. So, the light comes in. If this is turned yellow or opaque, then less light is coming out the
other side, and the sensor picks that up. And if none of this reaction happens, and this remains perfectly clear, the light going in equals the light going out, and essentially, you get a very good signal. What you’re doing is measuring the optical density. At a certain point, there is a threshold where, if the optical density is above that, then it’s considered positive. If it stays below that, then it’s considered background or negative.

As this exchange illustrates, a number of different factors are involved in conducting an EIA. Micro-wells coated with some of the proteins that make up HIV-1 and HIV-2, human antibodies, animal anti-human antibodies, substrate, and so on. These processes produce a reaction that is then measured by a laboratory technologist using a technical instrument. This test is performed at least twice for each sample.

I think it is noteworthy that what is being screened for in this test are antibodies to HIV, and not the virus itself. This first step in the screening regime relies on observing a reaction to the virus. For this reason, the presence of HIV could be missed during the window period, before the body in question has had a chance to fully develop its reaction to the virus. I will comment on this in more detail below. First, however, let me briefly discuss the confirmatory test.

The Western Blot

If, in one or both of the EIA tests, the measurement taken is above the threshold, in other words, if the test is considered reactive or positive, a further confirmatory test is performed. Whereas the initial screening test uses human antibodies to HIV as a marker to indicate the presence of the virus, the confirmatory test uses the component proteins of the virus itself, as these form a human-viral assemblage. This test is called the western blot. The same person who explained the EIA to me described the western blot in the following terms:
I 54: If you get a good, positive signal, the next step is usually a western blot. There are two types of tests which are licensed and approved for confirmation. One is a western blot, and one is an immuno-florescence test. In most places, particularly with the high volumes, we’re using a western blot assay […] What a western blot does is […] put the proteins on filter paper, but based on size, these proteins are spread out over the length of this filter paper. Then everything else is virtually exactly the same. You put this in a little bath, you add the patient’s serum. This time, what happens is, if the patient has antibodies, let’s say to p24, or gp41, or gp120, etc, the antibodies will stick on that little filter paper. You add a second detector antibody with an enzyme, for a colour reaction, and this time, what you end up getting are little bands that appear on this. Therefore, depending on the pattern of the bands, it will tell you whether, in fact, these are antibody specific for HIV, because this time you know exactly which proteins they are sticking to. There are certain criteria – it has to stick to at least three of the key proteins in order to be considered a positive.

The western blot test is a more refined, definitive way of testing for HIV. However, and as with the EIA, a range of complicating factors creep into the testing procedure. Additionally, I think it is noteworthy that what is being screened for here are viral components. Again, HIV itself, as a whole, functional viral entity, is absent from this picture.

*Stabilizing Instability*

It will be helpful, at this point, to position the above material in relation to Vicky Singleton’s (1998) illuminating work on the UK’s cervical screening program. Singleton’s ethnography of laboratory practices reveals that, contrary to popular belief about the capacity of laboratories to generate definitive answers, laboratories concomitantly stabilize and destabilize the results of their screening practices. This paradoxical situation does not invalidate the procedures of the screening program. If anything, Singleton argues, the
indeterminacy of these diagnostic procedures requires “that women have regular cervical smear tests” (1998: 95).

There are multiple factors that introduce instability into the screening process. These relate to intake procedures (information entry mistakes, for instance), sample contamination, threshold cases where difficult judgments must be made, and also to the way results are communicated: the wording of recommendations may be “problematic because a concern to detect and treat abnormalities is continually balanced against a concern not to promote unnecessary treatment and anxiety through highlighting cell changes that are insignificant or may revert to normal without treatment” (ibid. 91). Additionally, instability also derives from lab workers themselves who reflexively interpret and interrogate the results of their work (ibid. 92). There is a tremendous amount of pressure on lab workers to get the diagnosis right, and they develop multiple strategies to cope with this pressure. Some diagnoses are made, for instance, in conjunction with a reflection upon the patient’s age or whether a patient has child bearing capacity. At other times, diagnoses have to be made by attempting to consider the sample as though it were completely isolated from the patient. These practices reflect, Singleton argues, the emotive and pragmatic nature of this diagnostic work (ibid. 96-97).

In the previous chapter my description of the sample collection procedure illustrated how patients were excluded by the HIV testing regime. Singleton’s ethnography permits the imagination of how patients – or at least aspects of their data doubles – can be re-enrolled in a laboratory context. In my own conversations with laboratory technologists, it became clear that there were a multiplicity of different ways of communicating between the laboratory and the clinic. For example, I asked a laboratory technologist how she would
communicate with medical care practitioners upon discovering a positive case of communicable disease:

MF: OK, when you get a test, positive, say for influenza, and this has been from a nursing home, or maybe from a doctor’s office, how do you go back and communicate to the nursing home or the doctor’s office?

I 50: Usually by telephone. We do have one hospital that, if it’s positive, we send a fax. We have to get permission to fax, which is a bit of a production, but then I guess they have to be careful to ensure that it’s not going to the wrong place. But, normally by telephone. Telephone is the method of choice, because that way we get a person that we can talk to. Usually it would be a public health nurse, especially with an outbreak. They usually phone us to tell us that they’re coming too, most of the time, and they put their contact person on the form.

MF: [...] The government is wanting to invest in computer systems, iPHIS, for instance, the integrated Public Health Information System that they’re using in public health offices. That system hasn’t come over to labs yet, so most labs are still phoning and faxing. Do you think that would help, to have a computerized system to do that stuff, or do you find the phone to be sufficient?

I 50: I think that the phone is sufficient, because that way you’re talking to a real person. I mean, it might not be the same day. Usually, if that happens, we leave a message, like phone us back, we have results for you, and people are good. They usually phone back within an hour or two.

The phone, in this instance, is the medium of choice because it connects laboratory technologists and physicians with the least amount of extra work. The fax is a bit of a production, a bit more work. A computer-mediated communication is an unknown entity, though if iPHIS is anything to go by, it could be more of a production still.
There are several reasons why technologists would want to have an easy connection to the clinic. Numerous factors on the periphery of the laboratory intervene in the diagnostic process. The laboratory technologist quoted above touches on several of these in the following exchange:

MF: Reflecting on your day to day work, this job, what do you feel is working well, and what things would you like to see change?

I 50: I think, supplies. I mean, we’re pretty good, but sometimes, when you ask for something, you get it, but at the same time it’s also difficult, like [you’re asked] ‘do you really need this?’.

MF: Right, sorry to interrupt, but I can imagine that that would impinge upon the way you carry out a test. If you’re stressed about making sure the expensive test is conducted appropriately, might that stress make you more liable to make a mistake?

I 50: Well, for example, cells have to be made, and we get them from the [United] States, because there’s nobody in Canada that makes them, I guess. And sometimes, they don’t come, because of the long weekend, or they don’t make the airport, or whatever. And it delays our testing. I mean, we’ve got stuff in the fridge, and it’s very tense, if, for instance, a shipment is held up by customs or something. There’s got to be something that they can do, to avoid that. […] I think the only other thing is the duplication of specimens. An example might be that sometimes we get two different samples from the same patient, from different sites. But, it’s the same person, and you’re not going to find something different in this specimen and that specimen, especially if it’s respiratory. You’ll get a nose swab, and then you’ll get a suction. I don’t know if the doctors are informed or not.

MF: It makes more work?
I 50: It makes more work and you’re actually doing exactly the same thing to two specimens on the same person, where those cells could be used for somebody else. We can’t not do it, unless somebody up there tells us to stop doing it.

MF: That’s interesting. So you have two specimens, but presumably you only have one data sheet, so how does that work?

I 50: We give them different numbers. Lots of times it happens that you get one data sheet, but two specimens, and that makes some work. If they separate it, we’re good, but they usually don’t, and then we have to figure it out.

MF: So you would just get samples from a doctor, and, no matter what, you have to run the test unless someone more senior says that this isn’t appropriate?

I 50: Right, and most of our samples, a lot of them, are critical samples. They’re from babies, for instance, and it’s hard to go back and get further samples from them, so sometimes, if the sample wasn’t taken correctly, that makes more work for us. We try to salvage what we can, but sometimes it’s frustrating, the way they come in. We don’t really deal directly with the physician, in the sense that we have a courier that brings them in. So, it would be kind of nice if we had more contact with the doctors. Sometimes we do, when we’re phoning results we can ask, you know ‘next time, can you make sure…’ and they’ll say ‘oh, I didn’t know that…’ And it’s education for them too. […] I find, too, that we don’t have the same rapport. Like hospitals, you have your in-house doctors that you can talk to. But here, we don’t really, unless we pick up the phone, we don’t have that personal contact, which is kind of nice to have.

A number of noteworthy issues arise here. For instance, the availability of biomaterials could become a problem. Biomaterials must be produced. They cost money; hence, in addition to worrying about the results of a test, technologists must think about the cost of a
test. Are two tests really necessary where one should suffice? Poorly completed paperwork could cause duplication, something that technologists feel they have little control over. Additionally, samples travel by courier. The courier, what Romanow would call an ancillary (privatized) service, acts as an intermediary. It connects the laboratory to the clinic, enabling “action at a distance” (Latour 1987: 219). But it is this very distance that can put the diagnostic procedure into question. It complicates the work of the technologist, making it more difficult to intervene in clinical practice.

All of these complications, and all of the practices devised to deal with them, are what Mol refers to as coordination work. She writes: “Lab outcomes and the results of clinical diagnosis are supposed to line up. But sometimes they don’t. Then it requires some coordination work to still align them” (2002/2005: 66). This coordination work smoothes out differences. As Mol argues:

> A shared, coherent ontology is not required […]. Incompatibilities between objects enacted are no obstacle to medicine’s capabilities to intervene – as long as the incompatible variants of an object are separated out. This then, is what happens. The possible tensions between different variants of a disease disappear into the background when these variants are distributed over different sites (ibid. 115).

Taken together, lab processes, and the communicative practices and circuits that link the clinic with the lab, generate stability and smooth out difference. Crucially, however, in producing this kind of distributed stability, they also generate a different kind of artefactual instability.

Marginalized in this stream of complexity and complexity-management practices is, I will argue, the unruliness of HIV itself. By working in conjunction, the laboratory and the
clinic are very good at identifying whether or not a person is HIV-positive. However, reflecting on the fact that HIV tests target viral presence but not necessarily viruses, I am prompted to wonder whether the provincial screening-surveillance regime is adequate to the challenges posed by HIV? In sum, the multiplicity of practices designed to identify HIV produce their own instabilities. On the one hand, when the coordination work does not work as it is supposed to, this necessitates further coordination work. On the other hand, in a kind of catch-22, when the coordination work works it smooths out different variants creating a certain picture of an uncertain entity. There is, thus, an oscillation between certainty and uncertainty, the creation of certainty and its inevitable rupture. My claim hinges on the understanding that HIV is itself uncertain; it is uncertain about itself, about what, exactly, it will be. HIV thus resists the concretizing effects of the forms that screening-surveillance superimposes.

**Screening-Surveillance Technology: The Matter of HIV**

~ “We came to the laboratory in order to settle our doubts […] but we have been led into a labyrinth” (Latour 1987: 67).

The testing procedures described above are effective at identifying HIV in bodies and in populations. They are less effective, however, at identifying HIV itself. This has to do with the paradoxical meaning expressed by the phrase HIV itself. There is a sense in which the human immunodeficiency virus, by virtue of its very namesake, cannot exist itself, beyond the shelter of human cells. But, this paradox is merely logical. It rests upon a reified form of HIV; it elides a consideration of the matter of HIV. In this section, I argue that a consideration of the matter of HIV recalls an earlier conception of viruses, a conception that prevailed before viruses were concretized by laboratory visualizing procedures: it recalls
contagium vivum fluidum. Additionally, given the biological variability of HIV (see, for instance: Schuitemaker 1999: 43), I argue that the structure of the screening-surveillance gaze does not adequately grasp the material of the virus itself. It relies upon the identification of form at the expense of an engagement with matter.

In general terms, studies of RNA virus evolution tend to focus on their enormous amount of genetic variation (Holmes 2003: 543). This variability stems from their high mutation rate, as well as their short replication times. For instance, HIV-1 virus isolation from patients in different stages of HIV infection “showed that not only replicative capacity but also cytopathicity could vary between viruses” (Schuitemaker 1999: 44). What this seems to suggest is that the virus population designated by HIV changes itself in the course of infection. HIV changes over time.

Although it was initially supposed that HIV-1 would be genetically homogenous, research revealed incredible heterogeneity. Freed and Martin write:

No two HIV-1 isolates were identical. When subjected to nucleotide sequence analysis, even HIV-1 samples recovered from a single individual exhibited significant heterology. Some of the nucleotide changes resulted in amino acid substitutions (nonsynonymous) whereas others did not alter the protein sequence (synonymous). Although nucleotide changes were distributed throughout the HIV-1 genome, the greatest variability occurred in the gene encoding the envelop (Env) glycoprotein, gp 160 […] the term quasispecies was subsequently coined to describe the pool of diverse and changing populations of virus present in an individual infected with HIV-1 (2007: 2110 –emphasis mine).

Other proteins in HIV proved more stable, which was important for the development of HIV diagnostic tests. Nonetheless, the tremendous heterogeneity of HIV-1, arising from the reverse transcription process, high levels of virus production, high rates of genetic
recombination, as well as the large number of people carrying HIV, make the virus tremendously diverse (ibid. 2110). As Freed and Martin indicate, the virus does not easily fit into the species mould. It lives life at a different speed, enjoying a different duration than the species that coined the term *species*.

Arguably, a screening-surveillance regime that could be more adequate to the challenges posed by HIV would aim to scrutinize the liveliness of virus. The science of HIV reveals numerous different ways in which HIV is lively. Even setting aside the high degree of variability of HIV when viewed at the population-level, there are numerous indicators that virions themselves are “actants” (Latour 1999: 303) and ought to be defined, not merely in terms of presence or absence, but also in terms of what they do, and how they perform under laboratory conditions and *in vivo*. For instance, recent nanotechnological research has suggested that, quite apart from the difference that might be supposed to exist across individuated virus particles, the viral capsid, the protein coat that envelopes viral genetic information, can itself be a dynamic structure. As Douglas and Young argue, “it is likely that most virus capsids are dynamic metastable structures” (Douglas and Young 2006: 874). Additionally, single virus tracking techniques suggest that viruses “surf” across cell surfaces, exhibiting a degree of selectivity prior to attachment (Brandenburg and Zhuang 2007: 203).

Moreover, with reference to the protein spikes (gp120) that protrude from the surface of HIV-1, Zhou et. al. argue:

…HIV-1 envelope glycoproteins have revealed extraordinary diversity, manifest in a variety of immunodominant loops, as well as multiple overlapping mechanisms of humoral evasion, including self-masquerading glycan and conformational masking. These evolutionarily honed barriers of diversity and evasion have confounded traditional vaccine development (2007: 732).
In addition to exhibiting an *outer* dynamism, the nucleic acid of HIV also demonstrates an *inner* dynamic propensity. Analyzing the binding orientation of the reverse transcriptase (RT) enzyme, the enzyme that HIV brings into the cell in order to turn its RNA into DNA, Abbondanzieri et al. observe that the “spontaneous structural reorganization of the RT-substrate complex potentially allows the enzyme to rapidly explore multiple binding orientations that support distinct functions, thereby increasing replication efficacy” (2008: 188). At present, this kind of dynamism remains beyond the scope the screening-surveillance gaze.

In Ontario, the screening-surveillance of HIV is structured around the identification of viral markers. These markers take two forms: on the one hand are macro risk identities; on the other hand are micro protein identities. Built into the very structure of this surveillance, therefore, is a blind-spot: intensive differences, changes within these identity categories, are difficult, if not impossible, to see. How does a risk category, based on iterations of behaviour, chart the life-course of a person? How does a protein identity, based on size, shape and chemical affinity, chart the life-course of a virion, let alone a population of viruses?

Given this blind-spot, I think it is the more noteworthy that, in Ontario, once a person has been identified as HIV-positive, the province has the capacity to test for viral load, but not for drug-resistance, not for the ways in which the virus reacts to its perturbation with anti-retroviral drugs (I 54). In effect, the Ontario laboratory system can monitor a patient’s immune response to Highly-Active Anti-Retroviral Therapy (HAART), but not the response of the virus, not its mutations. Resistance testing is conducted in British Columbia, and blood samples that require this testing must enter another, inter-provincial, circulatory system.
Conclusion

With the approach of the fourth decade of the AIDS epidemic, or rather the fourth decade since AIDS was officially recognized in its epidemic form, the prospects for a cure seem bleak. Several high-profile clinical trials of anti-HIV vaccines and microbicides have failed (Thomas 2001; Check 2007). So great has this failure been that, following twenty-plus years of research in the field, Françoise Barré-Sinoussi, director of the Regulation of Retroviral Infections Unit at the Pasteur Institute in France, and one of the early elucidators of the structure of HIV, called for a return to basics and the development of new vaccination strategies. Just what these strategy should be remains open to question. Both the nature of retroviruses, and the difficulties involved in creating clinical trials for vaccine candidates, seem to have effectively blocked organized efforts to find a cure for HIV.

In this chapter, I have identified what I take to be a further difficulty blocking an adequate response to the challenges posed by HIV. This difficulty has to do with the manner in which the HIV screening-surveillance regime is configured, the level at which its gaze is directed. I opened this chapter by suggesting that, while laboratories produce certainty, they also generate uncertainty. Laboratories produce diagnostic results; however, in so doing, they entrench both the diagnostic tools and the settlements (concretizations) upon which those tools are based. This situation generates both stability and instability, both certainty and uncertainty.

To set up my argument it was first necessary to question the taken-for-grantedness, not only of HIV, but also of viruses in general. I did so by recalling a time before viruses were ascribed a concrete form, and then by describing the conditions that led to the concretization of viruses. Where HIV is concerned, concretization occurred as a result of
several factors, not the least of which was the resolution of an international dispute over priority, brokered at the highest levels of nation-state political machinery.

Setting aside the historical conditions of its emergence, I next focused on the ways that HIV tests must take aspects of HIV for granted. Interestingly, these tests screen for immune system reaction to HIV, or for the component parts of HIV, but not for HIV itself. This suggests, to me, that there is a blind spot built into the HIV screening-surveillance regime. Having accepted the concretization of HIV, the screening-surveillance regime cannot adequately contemplate the liveliness of the virus. It identifies the presence or absence of the virus, but beyond this, the virus itself stands as a marginalized local order of concern.

In order to suggest that the virus itself does things that seem to merit the attention of the screening-surveillance regime, I briefly touched upon recent scientific findings concerning the heterogeneity, diversity and flexibility of HIV. The question as to whether it is possible to construct a surveillance system capable of tracking disease in such fine-grained form remains open.
Chapter 7: Conclusion

Foucault, in *The Birth of the Clinic*, argues that death had to become a “concrete a priori of medical experience” before medical experience could “detach itself from counter-nature and become embodied in the living bodies of individuals” (1963/2003: 243). It is deeply paradoxical that death should have had to become a concrete a priori for the medical study of life. In a similar vein, it is deeply paradoxical that an immaterial conception of information, a conception that renders information dead a priori, should today be the organizing principle of large-scale, IT-mediated public health surveillance. It is deeply paradoxical, in other words, that dead information is the sought-after resource for producing knowledge about the life and health of the body politic.

The attempt to surgically excise information from its material dimensions is not so much an overt goal of IT-mediated surveillance as an effect of the convergence of multiple technologies and practices. These technologies – ranging from large-scale, networked computer systems, to administrative forms and classifications, to distributed diagnostic testing procedures and decision-aids – complicate, and are complicated by, public health surveillance practice. My concern is that these technologies are increasingly pushing public health surveillance practice into assemblages devoted more to the control of information about the public’s health, than to the public’s health per se.

These assemblages, of course, may be complied with, ignored, or resisted in the course of public health practice. This factor makes the study of public health surveillance practice of paramount importance. Such study reveals that practitioners, patients, and pathogens all live out material realities; all have a duration and a becoming that resists immaterialization. Paradoxically, this resistance to immaterialization propels the
intensification and globalization of public health surveillance assemblages, where these assemblages are organized by the immaterial conception of information.

Information, conceptually divorced from its material dimensions, treated clinically as a pure object upon which the knowing subject may act, becomes, in the IT imaginary, a substance that has no capacity for becoming. In other words, information becomes, in this imaginary, eminently knowable and eminently controllable. These apparent properties make immaterialized information an extremely desirable object, a bastion of certainty in an uncertain world. Whether these immaterial properties can be realized, however, is another question altogether.

Consequently, this dissertation raises questions about the viability of surveillance systems organized according to conceptions that hold information to be immaterial. By exploring different material dimensions of information, I have highlighted the multiplicity of assemblages that make public health surveillance possible. In an effort to picture their liveliness and heterogeneity, I have followed a micro-scoping path. Regardless of the order of magnitude at which public health surveillance is pictured, liveliness and heterogeneity remain key features. Even a public health surveillance directed towards the most microscopic levels of reality remains awash in material complexity. As this dissertation suggests, such complexity complicates health surveillance projects that attempt to immaterialize information.

In this conclusion I draw together the main themes of the dissertation. First, I concentrate on the politics of the immaterial as expressed in large-scale, IT-mediated public health surveillance systems. Second, I reflect on the local orders of concern that are being marginalized by the movement to create globally integrated systems of surveillance. Third, I conclude on the merits of picturing public health surveillance through a surveillance studies
lens. The approach taken in this dissertation reveals the many assemblages – the many different orders of concern – that must come into relation with each other in order to produce an evaluation of public health. Hence, this approach indicates the need for a more broadly inclusive discussion about the nature and goals of public health surveillance, not to mention a re-thinking of precisely what is meant by public health.

**The Politics of the Immaterial**

IT is more than a mere tool. Recognizing this fact is the first step towards an engagement with the politics of the immaterial embedded in large-scale IT. Like all technology, IT comes into being according to a series of decisions which, while technical, are always also political. Politics are thus embedded in the very architecture of technology.

I have argued, in this dissertation, that IT is often accorded an extraordinary power in discourse that promotes it as a solution to perceived crises. This has to do with the immaterial conception of information, a conception that holds that information, once instantiated in IT, is made immaterial. Immaterial information, it is supposed, has the power to transcend space and time. The conception seems to promise unparalleled control over the underlying structure of a chaotic world. However, as I indicated in chapter 2, the immaterial conception of information is founded on a paradox. At the same time that information was seemingly becoming immaterial, the material universe was seemingly becoming information.

Although immaterial information promised increased control, the informatization of the material universe made the achievement of such control infinitely more complex. Today, this contradiction drives the intensification of large-scale, IT-mediated surveillance. In an
attempt to overcome complexity, the tendency is to scale-up, to strive towards an ever-more
universal and objective perspective.

The emergent, interdisciplinary field of surveillance studies has engaged with the rise
of immaterial information and the concomitant intensification of surveillance. I reviewed
literature from this field in chapter 2 and argued that it contains several good resources for
exploring the material dimensions of information. However, I also noted that there is a
dearth of empirical work on surveillance in medical care and public health contexts. I
suggested that this might be because the field has privileged, for various reasons, the
surveillance of personal information. This dissertation, therefore, takes a surveillance studies
approach to public health surveillance. In so doing, it stands as an initial empirical
surveillance studies foray into the public health context. Additionally, it presents a novel
mode of analysis meant to capture processes (and consequences) beyond those that directly
impact persons.

Moreover, this dissertation provides a framework for characterizing the politics of
the immaterial in the context of public health surveillance. On the one hand, the pursuit of
immaterial information consumes material resources. On the other hand, this consumption
– an insatiable consumption, since it is directed towards an unrealizable end – is masked by
the immaterial conception of information. Since immaterial information appears to be so
powerful, it can be disconnected from its worldly concerns. In the context of large-scale,
IT-mediated public health surveillance, immaterial information is ideationally and
institutionally disconnected from its material bases. It objectifies the determinants of health;
it objectifies patients; it even objectifies the professionals who are organized to produce
health information. Consequently, in this context, the politics of the immaterial can be
categorized as a marginalization of local, material orders of concern.
Local Orders of Concern

Local orders of concern provide the material, spatial and temporal parameters for two Latourian concepts – matters of fact and matters of concern. These concepts are brought into specific topological relations through the observation of local orders of concern.

As I argued in chapter 3, sociology has a long-standing preoccupation with the marginalization of patients. However, this preoccupation has resulted in an under-theorization of the relationship between patient marginalization and other forms of marginalization. By showing how public health surveillance is imbricated with war-time, crisis-driven logics, my intent was to illustrate the conditions under which the politics of the immaterial achieved ascendency. The globalization of large-scale, IT-mediated surveillance systems moves ahead in the name of public health. However, such developments are crisis-driven and better characterized as disease surveillance than public health surveillance. To the extent that they fail to accommodate professional, patient, and even microbial heterogeneity, these systems will lean public health responses more towards control than care.

In chapter 4, with a focus on Ontario’s integrated Public Health Information System (iPHIS), I argued that the labour of public health practitioners was not adequately accounted for during the implementation process. I related this accounting error to the desire for clean information flows, a characteristic manifestation of the immaterial conception of information. By focusing on ways that information-processing practices mutate information, my aim was to show how this material dimension complicates notions about information’s capacity to transcend time and space. Additionally, the case of iPHIS illustrates a key consequence of the immaterial conception of information. To the extent that this conception accords information itself with the capacity to flow, it marginalizes the labour of
information processing. When there are incompatibilities between public health professionals and public health surveillance, serious questions are raised: when, and under what conditions, does public health surveillance hinder the provision of public health services?

In chapter 5, I turned to a second local order of concern marginalized by large-scale, IT-mediated surveillance. With a focus on HIV/AIDS surveillance in Ontario, I discussed the extra-corporeal circulatory system that transforms a patient’s blood into surveillance information. I also observed that patients tend to have little to no knowledge of this system. There are a number of important reasons for the exclusion of patients at this juncture of the screening and surveillance process. For instance, the diagnostic procedure is highly technical. Additionally, public health practitioners may require ‘distance’ from patients where their role requires them to exert coercive authority. Nevertheless, the effects of this exclusion, for both patients and public health, remain under-theorized. On the one hand, to the extent that public health surveillance leans interventions towards control, public health practitioners must turn knowledge about patients against patients. This creates an ethical and political dilemma, especially in situations where patients have limited means to engage with the knowledge that is being used to coerce them. On the other hand, to the extent that public health surveillance remains ideationally and institutionally disconnected from screening, the recursive aspects of surveillance will be difficult to engage with. In short, how will surveillance systems interrogate the way their feedback loops construct identities when those very identities are left out of the picture?

Large-scale, IT-mediated surveillance is problematic for the way that it marginalizes both professionals and patients. It is ironic that this marginalization, ostensibly justified by the need to track the distribution of microbes, is also bound up with the marginalization of
that very local order of concern. As I argued in chapter 6, the heterogeneity of HIV itself is not adequately captured by Ontario’s HIV/AIDS screening-surveillance system. The laboratory tests for HIV depend on the identification of proteins. In an analogous way, the epidemiological pre-classification of blood samples depends on the identification of risks. Neither of these identification processes, I contend, adequately captures the material identity of HIV, nor the material identity of patients identified as HIV-positive. Drawing from the history of virology, as well as from contemporary virology, I suggested, in chapter 6, that the screening-surveillance regime was inadequate to the challenges posed by HIV.

In sum, the exploration undertaken in this dissertation opens several avenues for future research. The following questions may now be asked in Ontario, as well as in other domains and jurisdictions:

• What are the conditions under which public health surveillance benefits the public’s health? Conversely, when, and under which conditions, does public health surveillance hinder the provision of public health services?
• How can surveillance systems become better at involving patient input about public health priorities? Additionally, how can surveillance systems best interrogate their role in the construction of health and disease identities?
• What mixture of centralization and local distribution is preferable given the specificity of the challenges posed by different manifestations of illness?

Moreover, how do conceptions of human health efface the liveliness of the “non-human” world, and how, in turn, does this make surveillance inadequate?

These broad questions chart the direction of future research.

To conclude, the novel analytic framework developed in this dissertation calls for an empirical, focused approach to surveillance. At the same time, it broadens the range of
concerns that must be factored in any evaluation of surveillance. By drawing from the field of surveillance studies, this dissertation has explored terrain that lies on the margins of traditional, instrumental evaluations of surveillance. Additionally, by undertaking an empirical investigation of public health surveillance practice in Ontario, this dissertation contributes material to an under-examined area of surveillance studies. Finally, by critiquing the immaterial conception of information, by showing how this conception implicitly dominates discourse on public health surveillance, this dissertation demonstrates the need for a material conception of information.
Notes

1 In 2008, on the basis of an extensive investigation into the 2001 anthrax attacks, the US Federal Bureau of Investigation indicated that the perpetrator of the attacks was very likely an American scientist employed by the US Department of Defense in biological weapons research.

2 Thanks to Roger Burrows for indicating the necessity of a note here. There has been considerable social scientific interest, recently, in the ‘nature’ of information (see, for instance, Gane 2005, Lash 2002, as well as Lash 2006 and Taylor 2006). For an exploration of the implications of Lash’s work in the medical care sector, see Nettleton and Burrows 2003. I am sympathetic to a number of the arguments made by Lash. However, in this dissertation, the work of Mol and Latour has been much more influential because of the way it emphasizes the empirical study of practice.

3 Drawing from Gilles Deleuze and Felix Guattari (1980/2000), Kevin Haggerty and Richard Ericson describe assemblages in the following terms:

‘Assemblages’ consist of a ‘multiplicity of heterogeneous objects, whose unity comes solely from the fact that these items function together, that they “work” together as a functional entity’ (Patton 1994: 158). They comprise discrete flows of an essentially limitless range of other phenomena such as people, signs, chemicals, knowledge, and institutions. To dig beneath the surface stability of any entity is to encounter a host of different phenomena and processes working in concert. The radical nature of this vision becomes more apparent when one realizes how any particular assemblage is itself composed of different discrete assemblages which are themselves multiple (2000: 608).

For Haggerty and Ericson, the convergence of different kinds of surveillance practices and processes marks the emergence of a surveillant assemblage. The surveillant assemblage is far from a stable entity with fixed boundaries; rather, it exists as a potentiality at the intersection of various media and purposes. It comes to fruition through “multiple connections across myriad technologies and practices…” (ibid. 609) and these multiple connections and combinations provide for “exponential increases in surveillance capacity” (ibid. 610).

4 See, for instance, the now classic ethnographic study of Closed Circuit Television (CCTV) by Norris and Armstrong 1999, as well as more recent ethnographic work on CCTV (for instance: Dubbeld 2003; Smith 2004; 2007). For a compelling argument in favour of using institutional ethnography as a method with which to study surveillance, see: Walby 2005.

5 The other three data-exemplars are Quebec, Alberta, and British Columbia. Together these four provinces make up 85% of the Canadian population, and over 95% of the reported HIV and AIDS diagnoses (Canada, PHAC 2006: 2).

6 I have taken methodological cues from Hird 1995 and 2002. Additionally, thanks are owed to Dr. Hird for, among other things, helping me to identify which groups to interview, and for helping me to clarify the presentation of my methodology.

7 A number of the people that I spoke with asserted that surveillance in public health was something very different from, say, surveillance in policing. Some favoured the term disease tracking over surveillance, arguing that their work could not properly be described as surveillance.

8 The distinction between these positions is structural, but it is also an artifact of this dissertation. In other words, while these different positions exist within the organizational structure of public health, they are not always so clean cut as a simplified presentation of research makes them out to be. Public health workers tend to wear many hats. That a manager may also be a nurse, or a nurse also an epidemiologist, ought not to be totally eclipsed by simplifications made here for ease of presentation.
Three health units were initially excluded from this study because investigatory phone calls yielded no potential contacts. For the 33 health units that were contacted, letters of information (generally sent to the Medical Officer of Health) were followed up either with an email or a phone call. Of the 33 health units that were sent letters of information, no participants could be solicited from 14 health units. Of these 14 non-participating health units, there were 10 units that simply did not respond to the letters of information or the follow-up emails and phone calls. Of the remaining four units, two declined to participate with no stated reason, while two declined to participate because of a lack of human resources. In these latter two cases, neither health unit had an epidemiologist, perhaps indicating a perceived inability to participate in a research project framed in terms of health surveillance.

Opening Doors conferences, which have been held annually across the province since 1990, are dedicated to addressing local HIV-related needs.

In ten cases, interview transcripts were not produced because participants did not want to be interviewed on the record. Additionally, in three cases, transcription was impossible owing to the poor sound quality of the recording.

Niklas Luhmann argues that the operation of observing includes the exclusion of the unobservable, especially “the unobservable par excellence, observation itself, the observer-in-operation” (2002: 86). While I do not accept Luhmann’s ontological proposition that there is a single world multiply framed (a Kantian position), I agree with his assertion that there is a fundamental paradox at the heart of the attempt to observe observation, or in this case, survey surveillance.

I adapt this point about the interconnection between ideational and institutional public health formations from Nicholas King, who argues that the history of public health demonstrates “both the ideological connection between humanitarian concerns, national security, and economic gain, and the sedimentation of these connections into the institutions of state public health and international health” (2002: 766).

I will elaborate upon what is meant by local orders of concern more fully in chapter 3. Briefly, I mean that the immediate material context (the local order of concern) is subordinated to the imperative to produce a global picture of communicable disease.

On the convergence between computer science and molecular biology, see also Fox Keller 1994. Fox Keller notes that cyberscience and molecular biology were products of the same historical moment. However, she argues, their models of causal structure “were running on two separate tracks, side by side, but in opposite directions” (1994: 311). This began to change, though, as the science of genetics moved into the computer age, and as computers became more necessary for sequencing genes.

Monads, Leibniz famously claims, “have no windows through which anything can come in or go out” (Leibniz, Monadology, s. 7, cited in Savile 2000: 228). Thus, although Leibniz wants to take for granted that monads must undergo continuous change (s. 10, ibid. 228), such change can only be discerned, in his metaphysics, by appealing a priori to the fact that it must be so (Savile 2000: 95).

Castells builds a set of further definitions on top of this understanding of information. An extended discussion of these definitions is beyond the scope of the present project. Briefly though, Castells articulates the idea of informational capitalism in order to characterize the emergence of the information age. Informational capitalism names the new techno-economic system that resulted from the coincident development of IT and capitalist restructuring (Castells 1996/2000: 18). Castells argues that without IT, global capitalism would have been a limited reality. “Thus,” he writes, “informationalism is linked to the expansion and rejuvenation of capitalism, as industrialism is linked to its constitution as a mode of production” (ibid. 19). The concept of informationalism enables Castells to distinguish between the information society and the informational society. Information society emphasizes the role of information in society. In contrast, informational society is used to indicate “the attribute of a specific form of social organization in which information generation, processing, and transmission become the fundamental sources of productivity and power because of new technological conditions emerging in this historical period” (ibid. 21). Moreover, the logic of the informational society is that of the network, enabled by IT, and characterized by new forms of social and corporate relating. Here, a
network is “a structural condition whereby distinct points (often called ‘nodes’) are related to one another by connections (often called ‘ties’) that are typically multiple, intersecting, and often redundant” (Barney 2004: 2).

18 The question of whether IT integrates these modalities “for the first time in history” remains open. See, for instance, Plant’s convincing argument that “the textures of woven cloth functioned as means of communication and information storage long before anything was written down” (1997: 65).

19 Castells is careful to qualify his argument throughout, a factor that needs to be acknowledged by any critique of his work. Nonetheless, it is precisely the ambivalence produced by these qualifications that gives rise to the immaterial conception of information.

20 According to the Canada Health Infoway, a non-profit, government-funded corporation tasked with accelerating the development of Canada’s health information infrastructure, an EHR can provide ‘each individual in Canada with a secure and private lifetime record of his or her key health history and care within the health system. The record is available electronically to authorized health care providers and the individual anywhere, anytime, in support of high-quality care’ (Canada, CHI 2002: 4). In this articulation, the EHR suggests a record of relevant information that transcends space and time. There is a considerable amount of literature devoted to the EHR (for a review, see: Canada, HC 2001), much of it centred on how this technology will make health care delivery more seamless, efficient, and cost effective (see, for instance: Richards et. al. 2005).

21 Yet, compare Berg, whose research is critical of “overly ambitious attempts to ‘replace’ the paper record…” (1999: 96).


23 As an aside, one classical sociologist yet to receive the attention of surveillance scholars is Harriet Martineau (1860-63/2003), whose writing contra the 1860 Contagious Disease Acts in the UK stands out as an early critique of the medical surveillance of women.

24 See also the 2003 edition of Surveillance & Society dedicated to Foucault and Panopticism.

25 Bowker and Star make this argument, for instance, in relation to interventions against tuberculosis (1999: 170-192).

26 Before long, it seemed likely that human molecular makeup could be loaded onto a computer and stored for perpetuity. As one geneticist working on the Human Genome Project put it, ‘we’ would soon be able to pull CDs out of ‘our’ pockets and declare: “Here is a human being; it’s me!” (Gilbert 1992: 96; see also: Van Dijck 2000). David Noble catalogs numerous shades of this millennial desire, often deeply embedded as a meta-reason underlying the development of technologies. The idea that technology would eventually enable ‘man’ to transcend ‘his’ body was frequently vocalized by prominent figures in various scientific communities. For instance, Marvin Minsky, an artificial intelligence researcher, notoriously described the brain “as nothing more than a ‘meat machine’ and regarded the body [as] ‘bloody mess of organic matter’” (Noble 1997/1999: 156). Additionally, James Watson, an early elucidator of the double-helix model of DNA, wrote how, for him, the “idea of genes’ being immortal smelled right” (Watson 1968/1996: 153; see also Noble 1997/1999: 181). Scientific advances seemed to promise, to some, an escape from the mortal coil.

27 However, see Nicholas King’s (2005) critique of the dual-use rationale for investing in a public health infrastructure oriented towards biodefense.
This connection was made repeatedly. For instance, Wald (2008) cites a 1951 New York Times article informing readers of the possibility that American cities could be enveloped by a dense smog of “disease germs” (166). The article stated:

Despite a grim outline of what might happen, General Creasy declared that the possibilities ‘are frightening only if we give way to panic or if we fail to insure that we are ahead of any other nation in knowledge and preparedness in this field.’ […] ‘Biological warfare is essentially public health and preventive medicine in reverse,’ General Creasy said. ‘Except for novel methods of achieving deliberate dissemination of pathogenic organisms, it is a form of warfare which nature has waged against man [sic] for thousands of years and against which modern health practices have produced effective defenses’ (Anonymous 1951: 18).

Additionally, in 1952, the Atlanta Journal and the Pittsburgh Press each reported Alexander Langmuir’s speculations that their respective cities were ideal targets for an attack using biological weapons. According to Langmuir, the still heat of the Atlanta night created conditions that were favourable for biological warfare because airborne microbes would be kept concentrated and close to the ground for long periods of time. In Pittsburgh, Langmuir listed several possible weaponized agents, including a form of the plague. According to Elizabeth Etheridge, these speculations were tempered by Langmuir’s action-oriented response: “don’t get panicky; get prepared” (Langmuir, cited in: Etheridge 1992: 61).

As a discursive strategy, the idea of an ontological battle against microbes might be a good way to mobilize resources; however, such a position is surely based on a “cursory and superficial understanding of organic materiality” (Hird 2002b: 103). Such a position ignores the fact that humans are heavily dependant on their microbes for survival. Moreover, as Myra Hird provocatively argues, “in our collective action […], human beings resemble beings that humans ironically revile…” (ibid. 103). “In evolutionary and species survival terms,” she writes, “human beings most resemble viruses which also survive by colonizing, and then consuming, new territories” (ibid. 104). Such ironies are beyond the scope of contemplation when they get subsumed under the crisis-driven immaterial conception of information.

Chief among the differences is the distinction drawn between surveillance and screening. In public health discourse, screening refers to the monitoring of an individual while surveillance refers to the monitoring of a population (see, for instance: Rose 1985).

In this respect, it resonates with the contemporary orientation towards preparedness. As Andrew Lakoff argues: “In contrast to population-security-based tasks such as public health provision and poverty relief, preparedness is oriented to crisis situations and to localized sites of disorder or disruption. These are typically events of short duration that require urgent response. Their likelihood in a given place demands a condition of readiness rather than a long-term work of sustained intervention into the welfare of the population. […] If population security builds infrastructure, preparedness catalogs it and monitors its vulnerabilities” (2006: 272 - citation omitted).

A very similar definition appears in Thacker and Berkelman 1992, and in Thacker and Koplan 2004. Additionally, similar definitions, but definitions which drop the phrase “all who need to know” appear in: Thacker et. al. 1989 and Thacker 1994. In Thacker et. al. 1989, the phrase “all who need to know” is substituted by the phrase “those who can apply the data to control and prevention programs” (188). This articulation maintains a distinction between, on the one hand, collection and dissemination of information, and on the other hand, control and prevention.

This definition can be seen in a provincial context too. For instance, citing the National Health Surveillance Network Working Group, the authors of Building an Innovative Foundation: A Plan for Ontario’s New Public Health Agency define health surveillance in exactly the same terms (Ontario, AITF 2005: 21).

Michael Hardt and Antonio Negri (2000, 2004), while they do not agree with “the generality of Agamben’s claim” (2004: 364), make a similar argument about the normalisation of the state of exception. They argue that war has become “the general matrix for all relations of power and techniques of domination, whether or not bloodshed is involved. […] This does not mean that war has been domesticated or its violence attenuated, but
rather that daily life and the normal functioning of power has been permeated with the threat and violence of warfare” (2004: 13). Others, for instance Bigo 2006, have argued that Agamben overestimates the extent to which the state of exception has become the norm.

35 In 2007, the World Health Organization estimated that there were between 30.6-36.1 million people living with HIV (WHO 2007a; WHO 2007b).

36 Surveillance for disease in the global population is a chief facet of the International Health Regulations (IHRs). Although the IHRs have a history that can be traced back to the international sanitary meetings that took place in Europe following the 1830 cholera outbreaks, the new regulations depart radically from previous international agreements, including the 1969 iteration of the IHRs. Michael Baker and David Fidler (2006) describe this departure in the following terms:

IHR 2005 expands the scope of the regulations’ application, strengthens WHO's authority in surveillance and response, contains more demanding surveillance and response obligations, and applies human rights principles to public health interventions. The most dramatic of these changes involves a new surveillance system that far surpasses what the IHR 1969 contained (1058).

37 The Emerging Infections report illustrates this orientation towards information technology. The authors of that report expressed frustration that there was “no single database from which a physician, researcher, health care worker, public health official, or other interested party can obtain information on disease incidence, antibiotic drug resistance, drug and vaccine availability, or other topics that might be relevant to infectious disease surveillance, prevention, treatment, and control” (4). Furthermore, they argued: “…given the current communications capabilities of personal computers and the relative ease with which information on a multitude of topics can be accessed, a database is not only technologically feasible but could be a valuable addition to U.S. surveillance efforts” (Lederberg et. al. 1992: 123).

38 Weir and Mykhalovskiy (2006) analyze the development of the Global Public Health Intelligence Network (GPHIN), a joint WHO-Health Canada initiative. Interestingly, they observe that this surveillance system ran into funding problems and had to seek paying partners, one of which was the US military. The WHO subsequently had to divest itself from the initiative, once the US military came on board, in order to avoid perceptions of bias. It continues to use the GPHIN, however, as a paying client.

39 At the same time that HIV was compromising the body’s immune system, the immune system was being figured in terms of surveillance and defense. Looking at popular accounts of the immune system from the mid-to-late 1980s, Emily Martin observes a dominant theme: the body is recurrently depicted as a “scene of total war” (1990: 411). In one account, the “…cells and molecules of the defensive network maintain constant surveillance for infecting organisms” (Tonegawa 1985: 72 -cited in Martin 1990: 414). In another account, the body’s cells are equipped with “…’proof of identity’ – a special arrangement of protein molecules on the exterior…” (Nilsson 1987: 21 -cited in Martin 1990: 421).

40 Taking William Bogard slightly out of context, a prefficient technology is “not merely ‘efficient,’ it is ‘prefficient,’ that is, it eliminates problems before they emerge, absolutely, before they even have the chance to become problems” (2006: 60).

41 I adapt this point about the local deconstruction of emerging infectious disease discourse from King (2002: 771).

42 For example, if information is immaterial, then it can be assumed that although its interpretation might change, information itself does not change. Thus, the Rosetta Stone remains transcendentally the same, while socially determined interpretations of it change. This view, however, requires that one understand as incidental and unimportant the very material of the Rosetta Stone itself, not to mention the conditions under which was rendered readable to a mass audience. The erosion of the stone, the measures protecting it from erosion, the dislocation of the stone from one cultural context, and its relocation in a different cultural context, are deemed unimportant by this view.
The 1867 *British North American Act*, the constitutional document that divides power between the federal and provincial governments, does not specifically assign responsibility for “health” to one level of government or the other (Ries 2005: 10). However, as a result of the enumeration of federal and provincial jurisdiction in sections 91 and 92 of this document, and as a result of jurisprudence pertaining to these sections, the provinces retain most of the jurisdiction over health services (Shah 2003: 357). Historically, Canada did not have a federal Department of Health until 1919, and the federal government’s influence over health matters was largely indirect, in the form of conditional grants to provinces (Cassel 1994: 290). These grants were used in an effort to coordinate and standardize provisions relating to health, and they remain a feature of health care delivery today. Additionally, a range of organizations undertake work that is germane to health surveillance. Shah (2003: 85-97) usefully categorizes these according to source type. For instance, Statistics Canada and the Canadian Institute of Health Information are two organizations that process health information. Statistics Canada conducts a census every five years and other health related surveys on a regular basis. The Canadian Institute for Health Information, an independent but federally created organization, maintains databases on everything from health human resources, to spending on health, to various health services ranging from The Canadian Joint Replacement register to the Therapeutic Abortions Database. The government also collects vital statistics, concerning births, marriages, and deaths. The Department of National Defence processes health related information for members of the Canadian Armed Forces, while Health Canada processes health related information for Aboriginal Peoples. Other examples of governmental organizations that process health information are Transport Canada, which collects information on traffic related injuries, Corrections Canada, which processes the health information of prisoners, and Citizenship and Immigration, which processes information about the health status of immigration applicants. The list goes on. Examples of non-governmental organizations involved in the processing of health information at a national level include the Association of Workers’ Compensation Boards of Canada, The Canadian Red Cross, and Canadian Universities. Queen’s University, for instance, runs the Canadian Agricultural Injury Surveillance Program. This list of laws and organizations is illustrative rather than exhaustive.

43 In this way, Bowker and Star continue, classification systems tend to substitute precision for validity: “That is, when a seemingly neutral data collection mechanism is substituted for ethical conflict about the contents of the forms, the moral debate is partially erased. One may get ever more precise knowledge, without having resolved deeper questions, and indeed, by burying those questions” (ibid 24).

An historic promise of IT is that it will reduce labour. Numerous studies, however, observe the different ways that IT can actually increase labour. For example, Ericson and Haggerty, who investigate the use of IT in policing, suggest that IT ratchets-up managerial expectations. In addition to helping police track suspects, IT also tracks police work. In a sense, the “computer terminal in the patrol car is a time-and-motion study that never ends” (1997: 10). Moreover, because of the apparent increased capacity of computers to generate and distribute knowledge, the compulsion to collect information is intensified. “What initially appears as an interesting technological convenience,” Ericson and Haggerty write, “quickly becomes an expectation of supervisors and of police officers themselves” (ibid. 10).

45 During my interviews with public health professionals, I asked, hypothetically, about what would happen if I were to have an HIV test in their catchment area. Not all public health professionals interviewed were familiar with HIV/AIDS screening, and I have excluded those who did not comment on this question from the present analysis.

This is not entirely true. As Sierra et. al. observe, in about 50% of cases of HIV-1 infection – the predominant strain in North America – individuals will develop flu-like symptoms in the first 4 weeks after infection, while in the other 50% of cases, individuals will remain asymptomatic (2005: 237). In this period, described as the *primary infection*, the level of CD4+ T-cells declines quickly, and then typically rebounds. Levels of CD8+ and B-cells also decline, but also typically rebound in 3 to 4 weeks following infection. In spite of this immune response, HIV is not entirely cleared from the body, owing to its “extraordinary replication kinetics […] and the high error rate of reverse transcriptase (RT), which allow for the constant generation and accumulation of genomic mutations (Dybul et. al. 2003: 1287 –note omitted). Following the primary infection, individuals typically enter a period of *clinical latency*, an asymptomatic period “accompanied by persistent viral replication in the lymph nodes and a rapid turnover of plasma virions and CD4+ T lymphocytes” (Sierra et. al. 2005: 237). During this period, “the number of CD4+ lymphocytes decreases continuously. As a consequence
the patient’s immune system is no more capable of controlling opportunistic pathogens and life-threatening AIDS-defining diseases emerge” (ibid. 237). Although HIV infection results in a decrease of CD4+ lymphocytes, the virus resides in, but does not cause cell death in other cells of the immune system, macrophages, for instance. Consequently, cells in which HIV does not cause cell death continue to reproduce HIV, while the cells that would mark these reproducers for immune response are in continual decline (Fan et. al. 1989/1994: 62).


49 During this time period (1992-2005), the sex was unknown in 683 of the 16,168 HIV-positive diagnoses.

50 In Ontario, between 1992 and 2005, the numbers of female AIDS cases reported, per year, were: 40, 36, 49, 53, 60, 33, 24, 37, 30, 39, 33, and 36.

51 Additional information on mother-to-infant transmission comes from the Canadian Pediatric AIDS Research Group. This group, which began collecting information on children born to HIV-infected mothers in Ontario in 1992, draws upon four sources: Hospital for Sick Children, Toronto; Children’s Hospital in Eastern Ontario, Ottawa; McMaster University Medical Centre, Hamilton; and St. Joseph’s Health Centre, London. Also, information on HIV-related deaths is obtained from the Ontario Vital Statistics office of the Registrar-General, as well as from Statistics Canada (Ontario, HIV-EMU 2007: 7).

52 Drawing from Ian Hacking, it can be argued that iPHIS participates in a deeper transformation than that engendered by the rise of statistical reasoning. For Hacking, the rise of statistical reasoning transforms the categories of cause and effect and is nothing short of “a metaphysical revolution” (1981/1991: 185). With regards to the way this metaphysical revolution affects persons, Hacking argues: “Who we are is not only what we did, do, and will do, but also what we might have done and may do. Making up people changes the space of possibilities for personhood” (1986: 229). In this sense, it can be argued that iPHIS changes the space of possibilities for understanding HIV/AIDS. It changes the epidemic space in which disease causation is comprehended; the way HIV-disease is pictured. The fact that iPHIS replaces a system meant to contribute clinical data to the epidemiology of HIV/AIDS, and the fact that it inadequately produces this clinical data for epidemiology, is significant. The inadequacies of iPHIS effectively marginalize the clinic as a site of epidemiological knowledge.

53 When a person has a positive diagnosis, their information is sent to provincial health officials. While there is no legal requirement to report HIV nationally, provinces and territories voluntarily report non-nominal information about HIV/AIDS to the federal Centre for Infectious Disease Prevention (Canada, PHAC 2006: 14).

54 Of the 26,461 HIV-positive tests conducted in Ontario between 1985 and 2005, 13,528 have been nominal, 10,515 have been non-nominal, and 1,610 have been anonymous. In 808 of these tests, information on the type of test performed is unknown (Ontario, HIV-EMU 2007: 76).

55 As this work is being written, Ontario is investing in a new testing technology: the point-of-care test. These rapid test-kits, which produce test results in under an hour, eliminate the need to send an initial blood sample to a laboratory for preliminary screening. If a patient has a reactive result with a point-of-care test, a blood-sample is sent directly to the Central Public Health Laboratory in Toronto for confirmatory testing.

56 For instance, insurance companies routinely screen potential clients for HIV. Additionally, persons donating blood or organs are routinely screened for HIV. These tests are usually performed outside of the purview of public health, by private laboratories. Positive test results are, nonetheless, legally reportable to public health under the HPPA, and these testing organizations are obligated to report to the responsible medical officer of health.

57 In June, 2007, the Ontario government announced an additional 24 anonymous testing sites, bringing the total number of anonymous testing sites in the province to 50.
Section 22 of Ontario’s *Health Protection and Promotion Act* states:

22. (1) A medical officer of health, in the circumstances mentioned in subsection (2), by a written order may require a person to take or to refrain from taking any action that is specified in the order in respect of a communicable disease. R.S.O. 1990, c. H.7, s. 22 (1).

**Condition precedent to order**

(2) A medical officer of health may make an order under this section where he or she is of the opinion, upon reasonable and probable grounds,

(a) that a communicable disease exists or may exist or that there is an immediate risk of an outbreak of a communicable disease in the health unit served by the medical officer of health;

(b) that the communicable disease presents a risk to the health of persons in the health unit served by the medical officer of health; and

(c) that the requirements specified in the order are necessary in order to decrease or eliminate the risk to health presented by the communicable disease. R.S.O. 1990, c. H.7, s. 22 (2); 1997, c. 30, Sched. D, s. 3 (1).

As noted in the introduction, names have been changed.

In this respect, the implementation of the test has gotten markedly better over time, as public health and general practitioners have learned from experience. However, and while there is not a wealth of empirical research in this area, some studies corroborate my finding that patients can feel as though they have little or no control over the testing situation (see, for instance: Leonard and Shap 1999; Tharao and Massaquoi 2001).


For instance, the Canadian *HIV/AIDS Epi Updates, August 2006* report states: “Screening pregnant women for HIV clearly represents an important opportunity to prevent the transmission of HIV to infants through perinatal transmission. It has been estimated that if such programs screened 90% of pregnant women across Canada, there would be a 65% reduction in the number of HIV-infected infants…” (Canada PHAC 2006: 45 – note omitted). This advice is buttressed by studies that favour implementing routine testing for pregnant women (see, for instance: Bitnun et. al. 2002, and Jayaraman et. al. 2003; see also Walmsley 2003, and O’Connor and MacDonald 2002).

This critique is linked to a long-standing critique of scientific reason, articulated perhaps most notably, by Henri Bergson. In this dissertation, my target is nothing so grandiose as scientific reason. There are a multiplicity of ways of reasoning within science, and as Prigogine and Stengers (1984: 93) argue, Bergson’s mistake was to equate the science of classical dynamics with the whole of science. Nevertheless, I think the point that Bergson makes about the tendency in science to spatialize time, to see only actual multiplicities where there are also virtual multiplicities and duration, is relevant here. For Bergson, science seemed to rely upon a kind of atemporal time. The reliance upon a series of adjacent states to describe time denied, he argued, duration, or time’s flow. He wrote: “time is what hinders everything from being given at once” (1946: 110). Bergsonian time, then, is “indetermination itself” (ibid. 110). As I will argue, the testing technologies used to visualize HIV are built upon an *a priori* understanding of the form of HIV, an understanding that subordinates the liveliness of the virus *in vivo*, the time of the virus as it endures in the body.
As with every rule, there are exceptions. Ghedin and Fraser (2005) discuss the Mimivirus, a giant among viruses. Mimivirus was found in the amoeba Acanthamoeba polyphaga, and when first observed it was mistaken for a bacterium because of its size and hairy appearance. The observers named it Mimivirus, for Mimicking Microbe (La Scola et. al. 2003).

My understanding of the history of the causal approach to disease is informed by Carter 2003.

Carter observes that the first postulate has to do with necessary causation while the second and third postulate have to do with sufficient causation. Necessary causation is a weaker proof of etiology than is sufficient causation because identifying the presence of an infections agent in all cases of disease does not prove that this agent causes the disease in question. The infectious agent could be an artifact of the disease, for instance.

In order to account for viral pathogens, a number of ‘revisions’ of Koch’s postulates have been suggested. These are summarized by Alfred Evans (1976), who also proposes his own 10 postulates. The increase to 10 postulates suggests how difficult it is to think about causation with respect to viruses. It is noteworthy that, even into the third decade of the AIDS epidemic, there continue to be people who call into question the causal relationship between HIV and AIDS. The debate between the so-called ‘AIDS dissidents’ and ‘AIDS mainstream’ persists, in large part, precisely because of the impossibility of establishing causation according to Koch’s postulates.

It is noteworthy, given the discussion to follow, that the publication of these findings about tobacco mosaic disease (TMD) were not without controversy. Shortly after the publication of Beijerinck’s 1898 paper, a note was published by Dimitri Ivanowski, claiming priority for the discovery that the causative agent of TMD passed through porcelain filters. This claim was based on work that Ivanowski had published in 1892. Kluyver argues, however, that Ivanowski did not appreciate the significance of his findings. This, he contends, fell to Beijerinck who, while acknowledging Ivanowski’s priority, elaborated the meaning of this discovery for the science of life (Kluyver 1940/1983: 120).

Latour and Woolgar (1979) also make this point, and Latour recapitulates it again in 1987.

Protein 24 (p24) refers to the capsid protein that encases the nucleic acid of HIV, while glycoprotein 41 (gp41) and glycoprotein 120 (gp120) are the protein sub-units that together form the protein ‘spikes’ on the surface of HIV, of which there are generally about 72 on mature virions (Sierra et. al. 2005: 234).

A point of clarification is necessary here. I was not speaking with this laboratory technologist specifically about HIV screening. As noted above, the primary manufacturer of HIV tests for the province of Ontario (in 2007) is the American company Abbott Laboratories. Abbott maintains a branch plant in Ontario, meaning that Ontario’s public health labs do not have supply-side issues with HIV-test kit procurement. Nonetheless, I think the issue of biomaterial distribution is significant. Biomaterial substrates are an essential component of the HIV test, and tests cannot be performed in the absence of test kits.

Mutations in the env gene, the gene that codes for the amino acid sequence of the virus envelope proteins, already make it difficult for antibodies to successfully bind to HIV.
References


## Appendix: List of Interviews and Interview Guides

### List of Interviews

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**Laboratory Professionals**

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**MoH = Medical Officer of Health; MoH(A) = Assistant or Associate Medical Officer of Health**

**Interview Guides**

The following interview guides present a rough outline of the questions asked during my interviews with study participants. Owing to the open-ended nature of these questions, the scope of the actual interview transcripts is not necessarily entirely reflected in the questions below.
Public Health Nurses, Epidemiologists, Managers and Doctors

- Can you please tell me about your current occupation, the kind of work that you do? Are you actively engaged in health surveillance (and if yes, health surveillance of what kind/s)?

- I'm interested in where personal health information goes, and how it becomes surveillance data. What is health information to you?

- Can you tell me about the kind of health information you use in your work? Do you ever use people's personal health information?

- If yes, can you tell me about where it goes - for example, even just in your office, where does it go?

- If you use aggregate data, what sort of data processor/database technology do you use? Perhaps these questions are too broad...

- Let us consider a hypothetical case. I tell my doctor that I have engaged in unprotected intercourse with several partners and am concerned that I have contracted HIV. My doctor advises me to have a blood test. What is your understanding of what happens to my health information (test results) from here on? Can you tell me where my health information goes?

- Can you tell me how one person's health information eventually becomes part of the aggregate data of health surveillance?

- We can stick with the example of HIV here. Can you tell me, if I have tested positive, what kind of information is included in my file, and to whom is it disseminated? Who has access to this information?

[I will be asking the following set of questions to all interviewees - the goal of these questions is to have interviewees reflect on broad issues related to health surveillance]

- How do you define health? Illness? Disease? What does it mean to you to “test positive”?

- Reflecting on what we've just spoken about, can you give me a nutshell definition of health surveillance?

- In general terms, can you tell me your thoughts about the health surveillance we have been discussing? Reflecting on current practices, what do you feel is really working here? What are some things that you would change?

- Do you have anything else to add, or would you like to ask me any questions?
Laboratory Technologists, Scientists, and Infectious Disease Specialists

- Can you please tell me about your current occupation, the kind of work that you do? Do you consider yourself to be engaged in health surveillance?

- I’m interested in where personal health information goes, and how it becomes surveillance data. What is health information to you? Is health information different from health data? Can you tell me about the kind of health information you use in your work? If you use aggregate data, what sort of data processor/database technology do you use?

- Let us consider a hypothetical case. I tell my doctor that I have engaged in some ‘high risk’ behaviour and am concerned that I have contracted HIV. My doctor advises me to have a blood test.

- Can you tell me what is involved in a blood test? How do procedures differ in anonymous, nominal, and non-nominal tests?

- What is your understanding of what happens to my health information (test results) from here on? Can you tell me where my health information goes (in the lab)?

- Can you tell me how one person’s health information eventually becomes part of the aggregate surveillance data for national statistics?

- We can stick with the example of HIV here. Can you tell me, if I have tested positive, what kind of information is included in my file, and to whom is it disseminated? Who has access to this information?

[I will be asking the following set of questions to all interviewees - the goal of these questions is to have interviewees reflect on broad issues related to health surveillance]

- How do you define health? Illness? Disease? What does it mean to you to “test positive”?

- Reflecting on what we’ve just spoken about, can you give me a nutshell definition of health surveillance?

- In general terms, can you tell me your thoughts about the health surveillance we have been discussing? Reflecting on current practices, what do you feel is really working here? What are some things that you would change?

- Do you have anything else to add, or would you like to ask me any questions?
Patients

- I’m interested in finding out about how people’s information becomes data for public health surveillance. Basically, I’m interested in how the public health system handles personal information. Can you tell me where your personal health information is, and who might have access to it?

- I’d like to ask you some personal questions, and you don’t have to respond if they make you feel uncomfortable in any way –
  - We’re talking today because you’ve had one or more experiences of ‘being tested’. Can you tell me, first of all, what that experience was like?
  - Did you feel like you had control over the situation?
  - Someone took a sample from your body - Can you tell me what happened to that sample?
  - Where did it go, and what tests were performed?

[I will be asking the following set of questions to all interviewees - the goal of these questions is to have interviewees reflect on broad issues related to health surveillance]

- How do you define health? Illness? Disease? What does it mean to you to “test positive”?

- Reflecting on what we’ve just spoken about, can you give me a nutshell definition of health surveillance?

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