

# OVERLY INTIMATE SURVEILLANCE: WHY EMERGENT PUBLIC HEALTH SURVEILLANCE PROGRAMS DESERVE STRICT SCRUTINY UNDER THE FOURTEENTH AMENDMENT

MARGARET B. HOPPIN\*

*New York City's AIC Registry is a paradigm of "emergent" public health surveillance: It subjects a population with a non-communicable, non-exposure-related health condition to individualized, ongoing, and intimate government surveillance. In so doing, it employs a surveillance model that was developed in the context of serious contagious disease and was justified in part by the efficacy of government interventions to prevent contagious disease from spreading. This justification for the surveillance model does not apply to the principal present-day threats to public health: obesity and other chronic conditions like diabetes. In addition, emergent public health surveillance mimics three features of law enforcement and national security surveillance that courts and commentators have found both troubling and relevant to the scope of privacy protections afforded under the Fourth Amendment. Like security programs, emergent public health surveillance involves comprehensive, intimate and individualized surveillance, employs electronic data collection systems which have a low marginal cost and to which data mining techniques are easily applied, and scrutinizes politically vulnerable domestic populations. Building in part on Fourth Amendment challenges to, and critical commentary about, security surveillance programs, this Note argues that emergent public health surveillance programs intrude upon a fundamental privacy interest. Accordingly, they should receive strict scrutiny under the Fourteenth Amendment. The constitutional inquiry should turn in part upon the efficacy of the public health intervention enabled by the challenged surveillance program.*

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\* Copyright © 2012 by Margaret B. Hoppin. J.D., 2012, New York University School of Law; A.B., 2005, Harvard College. My deepest thanks to Judge Robert A. Katzmann for his extraordinary encouragement and guidance during the writing process. I am grateful to Professors Mary Jo Strandburg and Sylvia Law for their comments. I am indebted to the members of the *New York University Law Review*, especially to Nathan Richards and Matthew Kelly. I would also like to thank my father, Charlie Hoppin, for being a gentle skeptic and an inexhaustible line editor. All errors are my own.

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INTRODUCTION

Lawmakers, academics, and the American public have expressed increasing concern about three features of government surveillance: comprehensive and intimate surveillance of individuals, the creation of large databases to which sophisticated data mining techniques can be applied, and the targeting of politically vulnerable domestic communities. To date, concern about government surveillance and data collection has focused primarily on security surveillance.<sup>1</sup> Comparable recent developments in government public health surveillance have received little attention in contrast.<sup>2</sup>

The history of public health surveillance and interventions has been extensively studied,<sup>3</sup> but most chapters of that history focus on communicable diseases.<sup>4</sup> The model of public health surveillance that

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<sup>1</sup> In this Note, the term “security surveillance” refers to government surveillance in both national security and law enforcement programs.

<sup>2</sup> See, e.g., AMY L. FAIRCHILD ET AL., *SEARCHING EYES: PRIVACY, THE STATE AND DISEASE SURVEILLANCE IN AMERICA* 252 (2007) (“[P]ublic health surveillance has, for the most part, drawn little attention. The concerns of those responsible for developing, enhancing, and securing disease registries have centered on technical and administrative matters.”).

<sup>3</sup> See generally JAMES COLGROVE, *EPIDEMIC CITY: THE POLITICS OF PUBLIC HEALTH IN NEW YORK* (2011) (recounting the history of public health activities in New York City); MICHAEL A. STOTO, RAND CORP., *PUBLIC HEALTH SURVEILLANCE: A HISTORICAL REVIEW WITH A FOCUS ON HIV/AIDS* (2003) (describing the history of HIV/AIDS surveillance); Stephen B. Thacker, *Historical Development*, in *PRINCIPLES AND PRACTICE OF PUBLIC HEALTH SURVEILLANCE* 1 (Lisa M. Lee et al. eds., 2010) (recounting the history of health surveillance in the United States).

<sup>4</sup> See, e.g., COLGROVE, *supra* note 3, at 7–9 (describing the development of New York City’s public health infrastructure as driven exclusively by the need to prevent the spread of contagious disease from the mid–nineteenth century until at least the early 1960s); Emily K. Abel, *Taking the Cure to the Poor: Patients’ Responses to New York City’s*

was developed to fight communicable disease has two components: conducting nonconsensual, intimate surveillance of persons with a particular disease or health condition and maintaining databases of individually-identified information.<sup>5</sup> Historically, this enabled government interventions that prevented the spread of contagious disease.<sup>6</sup> This model was traditionally justified both by the nature of the risk created by communicable diseases and by the efficacy of government interventions to mitigate that risk.<sup>7</sup>

Today, *non-communicable* chronic diseases and obesity present the most serious threats to public health and health care costs,<sup>8</sup> and public health surveillance programs have accordingly begun to target them.<sup>9</sup> Notably, government agencies have begun to target non-communicable, chronic diseases through what I call the “emergent” model of public health surveillance. In the emergent model, the government (i) conducts nonconsensual, ongoing, and intimate surveillance of a large number of people because they have a non-communicable health condition and (ii) maintains individually-identified databases of the information gathered.

The problem is that emergent government surveillance programs invade a very intimate sphere of personal privacy, despite the fact that the original justifications for doing so do not apply to non-

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*Tuberculosis Program, 1894 to 1918*, 87 AM. J. PUB. HEALTH 1808 (1997) (describing multiple public health surveillance programs and interventions that targeted tubercular patients in New York City).

<sup>5</sup> See *infra* notes 21–26 and accompanying text (defining modern public health surveillance).

<sup>6</sup> See *infra* notes 12–14 and accompanying text (describing effective interventions enabled by New York City’s nineteenth-century surveillance and monitoring of tubercular patients).

<sup>7</sup> See *infra* note 23 and accompanying text (noting that historical justifications for intervention emphasized stopping the spread of communicable diseases).

<sup>8</sup> For example, approximately 26 million Americans have diabetes, 79 million have prediabetes, and one in three adults could have diabetes by the year 2050 if current trends persist. Press Release, Ctrs. for Disease Control & Prevention, *More Than a Third of Adults Estimated To Have Prediabetes* (Jan. 26, 2011), available at [http://www.cdc.gov/media/releases/2011/p0126\\_diabetes.html](http://www.cdc.gov/media/releases/2011/p0126_diabetes.html). Furthermore, in 2010, 35.9% of Americans over the age of 20 were obese, and an additional 33.3% were overweight. See *Faststats: Obesity and Overweight*, CTRS. FOR DISEASE CONTROL & PREVENTION, <http://www.cdc.gov/nchs/fastats/overwt.htm> (last visited Oct. 18, 2012). Obesity-related health conditions cost approximately \$160 billion annually in direct medical costs and approximately \$450 billion in indirect costs. Obesity-related health care costs have doubled in the last decade and are predicted to double again by 2018. See *The Real Cost of Obesity*, MCKINSEY Q. (Jan. 2011), [http://www.mckinseyquarterly.com/newsletters/chartfocus/2011\\_01.htm](http://www.mckinseyquarterly.com/newsletters/chartfocus/2011_01.htm).

<sup>9</sup> See, e.g., Michael A. Stoto, *Public Health Surveillance in the Twenty-First Century: Achieving Population Health Goals While Protecting Individuals’ Privacy and Confidentiality*, 96 GEO. L.J. 703, 707 (2008) (“Over the course of the twentieth century, the primary cause of death shifted from infectious to chronic diseases; as a result the focus of surveillance shifted to populations rather than individuals.”).

communicable, non-exposure related conditions. Moreover, proponents of emergent programs have not articulated a satisfactory alternative justification for significantly invading the privacy of people with non-communicable health conditions.

This Note has three parts. In Part I, I briefly summarize the salient features of public health surveillance programs in the United States. Against that baseline, I describe New York City's A1C Registry as the paradigm of emergent public health surveillance and explain why emergent programs are likely to proliferate.

In Part II, I argue that emergent forms of public health surveillance intrude upon a privacy interest that courts should recognize as fundamental for purposes of the Fourteenth Amendment's Due Process Clause. The argument proceeds in two parts. First, despite a widespread assumption to the contrary, judicial precedent does not require highly deferential review of emergent programs. Although federal courts reviewing privacy-based challenges to public health programs have historically applied deferential standards of review,<sup>10</sup> those programs differ in essential respects from emergent public health surveillance. Furthermore, several opinions suggest that a more stringent standard of review would apply if the scope of surveillance increased, as I argue that it has. Second, comparable features of security surveillance programs have raised considerable public concern and have prompted some courts to expand the scope of privacy protections under the Fourth Amendment. Given the dearth of commentary on emergent public health surveillance programs, recent Fourth Amendment jurisprudence and critical commentary developed in the context of security surveillance provide useful guideposts. In particular, these paradigms help to delineate the privacy interest at stake in emergent public health surveillance programs. Part II concludes by explaining that, because they infringe upon a fundamental interest, emergent programs should receive strict scrutiny.

In Part III, I propose several factors to include in the constitutional analysis of emergent public health surveillance programs. Most important, the narrow tailoring requirement that would apply under a strict scrutiny analysis should examine the likelihood that the public health interventions enabled by the challenged surveillance program are effective. In the context of non-contagious diseases, efficacy should mean improvement or risk reduction in the health of the population targeted for surveillance. Applying the proposed analysis to

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<sup>10</sup> The standard of review varies across the circuit courts of appeals, but most apply either a deferential balancing test or rational basis review. *See infra* notes 82–87 and accompanying text (describing variation across circuits).

New York's A1C Registry, I conclude that the program may be unconstitutional.

## I

### PUBLIC HEALTH SURVEILLANCE

#### A. *Modern Public Health Surveillance*

The history of public health surveillance and public health interventions is both fascinating and complicated: A full account is far beyond the scope of this paper.<sup>11</sup> However, two observations based on that history frame my argument. First, the basic features of modern public health surveillance are not new; they were developed as responses to serious contagious disease. Second, public health surveillance in the United States has, in general, enabled interventions which—criticisms aside—have effectively addressed the public health crises they targeted.<sup>12</sup> To give just one example, the surveillance and interventions conducted using New York City's nineteenth-century tuberculosis registry prevented the spread of tuberculosis.<sup>13</sup> The program was accompanied by an impressive array of free services that helped to prevent and treat the disease. City and charitable organizations disinfected homes after a tubercular patient had moved or died, treated patients in facilities established across the City, created open-air programs for children and adults, and provided financial and logistical aid to tubercular patients.<sup>14</sup> Other municipalities offered similar services to patients.<sup>15</sup>

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<sup>11</sup> According to one scholar, the first example of a surveillance-based public health intervention likely took place in the early 1300s, when public authorities boarded ships near the Republic of Venice and prevented people who presented symptoms of bubonic plague from disembarking. Thacker, *supra* note 3, at 1.

<sup>12</sup> I make no larger claim about the relative virtues and vices of specific interventions. For thoughtful criticisms of early government surveillance and intervention programs, see, for example, FAIRCHILD ET AL., *supra* note 2, at 45, which describes disproportionate restrictions imposed upon indigent tubercular New Yorkers, and Abel, *supra* note 4, at 1809–13, which further describes hardships imposed on poor families by New York's tuberculosis programs.

<sup>13</sup> New York City implemented a system of mandatory tuberculosis reporting, supervision, and interventions in 1897. FAIRCHILD ET AL., *supra* note 2, at 41. Government nurses were to visit every tubercular patient regularly and assess their living conditions, finances, nutrition, and the health of their family members. *Id.* The New York City Department of Health maintained a registry with detailed reports about every patient. *Id.*

<sup>14</sup> Abel, *supra* note 4, at 1809, 1813.

<sup>15</sup> See SHEILA M. ROTHMAN, *LIVING IN THE SHADOW OF DEATH: TUBERCULOSIS AND THE SOCIAL EXPERIENCE OF ILLNESS IN AMERICAN HISTORY 187* (1994) (noting that by 1904, fifty-nine cities had passed ordinances requiring health providers to supply names and addresses of tuberculosis patients and dispatching inspectors to begin surveillance).

While public health surveillance has undergone radical changes<sup>16</sup>—with technological developments, epidemiologic shifts, and the rapid expansion and coordination of public health surveillance activities transforming a disparate collection of municipalities, each battling contagion, into a sophisticated, coordinated, and pervasive public health apparatus—the purpose remains the same: to collect and compile information about sick people over time, and then use that information to protect the public health. A cursory review of government public health activities since the late medieval period demonstrates that “[t]hroughout history, governments have performed their public health role by . . . taking steps to prevent the spread of epidemics.”<sup>17</sup> Mandatory quarantine programs—“features of most port towns” in colonial America—provide a dramatic example of surveillance-based public health interventions.<sup>18</sup> The relevant point is that surveiling individuals to protect the public health is anything but new. Indeed, the New York City Department of Health and Mental Hygiene intentionally modeled the A1C Registry—the paradigm of emergent public health surveillance—upon nineteenth-century surveillance and intervention programs that targeted tuberculosis.<sup>19</sup> The innovations—and the problems—at the heart of emergent programs are that they target individuals who pose no health risk to others, and they employ technology that enables surveillance that is virtually unlimited in scope.

Several features of “modern” public health surveillance, or public health surveillance as it has been practiced in the last seventy years,<sup>20</sup>

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<sup>16</sup> See, e.g., *Preface to PRINCIPLES AND PRACTICE OF PUBLIC HEALTH SURVEILLANCE*, *supra* note 3, at vii (describing the “many developments [that] have transformed the landscape of public health surveillance” between 2000 and 2010).

<sup>17</sup> Wendy E. Parmet, *Health Care and the Constitution: Public Health and the Role of the State in the Framing Era*, 20 HASTINGS CONST. L.Q. 267, 281 (1993).

<sup>18</sup> *Id.* at 293. See also *id.* at 287–93 (describing quarantine legislation and practices in the Massachusetts Bay Colony).

<sup>19</sup> See COLGROVE, *supra* note 3, at 255 (noting that Thomas Frieden, then-Commissioner of the Department, consciously modeled his approach on that of Dr. Hermann Biggs, who led the aggressive effort to combat tuberculosis in New York City at the turn of the twentieth century).

<sup>20</sup> In 1963, Alexander D. Langmuir of the Communicable Disease Center (now the Centers for Disease Control and Prevention (CDC)), published a seminal article that defined modern public health surveillance. Alexander D. Langmuir, *The Surveillance of Communicable Diseases of National Importance*, 268 NEW ENG. J. MED. 182 (1963), reprinted in *THE CHALLENGE OF EPIDEMIOLOGY: ISSUES AND SELECTED READINGS* 855 (Carol Buck et al. eds., 1988). Langmuir’s formulation—with its emphasis on data collection, analysis, and dissemination—remains the basis of the CDC’s definition of public health surveillance. See, e.g., Lisa M. Lee & Stephen B. Thacker, *The Cornerstone of Public Health Practice: Public Health Surveillance, 1961–2011*, in 60 MORBIDITY AND MORTALITY WEEKLY REPORT 15 (Supp. 2011), available at <http://www.cdc.gov/mmwr/preview/mmwrhtml/su6004a4.htm> (noting that Langmuir “separated the discipline of surveil-

establish a baseline against which emergent forms of public health surveillance can be compared. First, modern public health surveillance encompasses two distinct activities: case surveillance and statistical surveillance. Case surveillance involves identifying individuals with certain diseases and taking action to prevent the disease from spreading to others.<sup>21</sup> As described, case surveillance has historically “been used for communicable diseases capable of causing great harm to the entire population if allowed to spread.”<sup>22</sup> In addition, the “loss of privacy involved with this type of surveillance has been justified in terms of disease averted.”<sup>23</sup> In contrast, statistical surveillance focuses on populations and does not require individually-identified data. Public health professionals use statistical surveillance to identify trends and to develop public health policy priorities.<sup>24</sup> Prior to the 1950s, public health surveillance generally referred to case surveillance, but by the middle of the twentieth century, statistical surveillance had become the norm.<sup>25</sup> The focus switched from individuals to diseases, and from prompt action to “the systematic collection of pertinent data . . . the orderly consolidation and evaluation of these data, and . . . the prompt dissemination of results to those who need to know.”<sup>26</sup>

Second, modern public health surveillance targets a wide array of health problems other than communicable diseases. Public health surveillance activities now monitor cancer, birth defects, occupational disease, medical error, immunizations, Alzheimer’s and dementia, diabetes,<sup>27</sup> and other chronic conditions.<sup>28</sup> Third, modern public health

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lance from the other activities of public health” with his 1963 article and brought about the advent of the modern public health surveillance system).

<sup>21</sup> Stoto, *supra* note 9, at 704.

<sup>22</sup> *Id.*

<sup>23</sup> *Id.*

<sup>24</sup> *Id.*

<sup>25</sup> See Alexander D. Langmuir, *William Farr: Founder of Modern Concepts of Surveillance*, 5 INT’L J. EPIDEMIOLOGY 13 (1976), available at <http://www.epidemiology.ch/history/PDF%20bg/Langmuir%20AD%201976%20william%20farr%20-%20founder%20of%20modern%20concepts.pdf> (“Until 1950 *surveillance*, as used in the public health setting, defined the specific but limited function of watching contacts of serious diseases such as plague, smallpox, typhus and syphilis. . . . Beginning in 1950 in the United States the term *surveillance* was applied to specific diseases rather than to single individuals.”).

<sup>26</sup> Thacker, *supra* note 3, at 5. In the last decade, however, case surveillance has also been used to combat infectious diseases like severe acute respiratory syndrome (SARS). Stoto, *supra* note 9, at 706.

<sup>27</sup> Vermont created an *optional* registry for diabetics in 2004. People who opt in to the program receive certain diabetes management support services. See, e.g., Charles D. MacLean et al., *Diabetes Decision Support: Initial Experience with the Vermont Diabetes Information System*, 96 AM. J. PUB. HEALTH 593 (2006) (describing the opt-in registry and related decision support software for diabetes care providers).

surveillance sometimes uses sophisticated technology.<sup>29</sup> It is increasingly becoming a network of integrated data systems,<sup>30</sup> in which disease registries play a central role.<sup>31</sup>

## B. Emergent Forms of Public Health Surveillance

### 1. The Model: New York City's A1C Registry

In January of 2006, the New York City Department of Health and Mental Hygiene (the Department) launched the A1C Registry,<sup>32</sup> a program that conducts nonconsensual surveillance of diabetic New York City residents.<sup>33</sup> The A1C Registry “marks the first time that the government has mandated name-based reporting of a chronic, noninfectious disease not caused by an environmental toxin.”<sup>34</sup> The program requires laboratories and other facilities that either operate in New York City or draw specimens from city residents to report the results of a variety of blood tests collectively termed “Hemoglobin A1C tests.”<sup>35</sup> Labs are also required to report personal information

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<sup>28</sup> See Stoto, *supra* note 9, at 707 (describing multiple cancer registries, as well as surveillance activities that target occupational morbidity and mortality, medical error, and adverse effects of drugs and vaccines).

<sup>29</sup> For example, “syndromic” surveillance systems analyze a vast array of data sources, including human behavioral patterns, to detect possible disease outbreaks and/or bioterrorist attacks as they are occurring. Kenneth D. Mandl et al., *Implementing Syndromic Surveillance: A Practical Guide Informed By the Early Experience*, 11 J. AM. MED. INFORMATICS ASS'N 141, 141–44 (2004).

<sup>30</sup> See FAIRCHILD ET AL., *supra* note 2, at 241 (describing the development of systems that could “assure vital information collected could be easily shared among programs, across county lines, and among states”).

<sup>31</sup> For example, the National Cancer Institute's Surveillance, Epidemiology, and End Results Program (SEER) collects and publishes cancer incidence and survival data from population-based cancer registries that cover approximately 28% of the U.S. population. *Surveillance, Epidemiology and End Results Programs*, NAT'L CANCER INST., <http://seer.cancer.gov> (last visited Oct. 1, 2012). National Cancer Institute staff work with state agencies to harmonize data collection and facilitate data pooling. *Overview of the SEER Program*, NAT'L CANCER INST., <http://seer.cancer.gov/about/overview.html> (last visited Oct. 1, 2012).

<sup>32</sup> In 2005, the New York City Board of Health unanimously voted to create the program by amending the City's Health Code. Amy L. Fairchild & Ava Alkon, *Back to the Future? Diabetes, HIV, and the Boundaries of Public Health*, 32 J. HEALTH POL. POL'Y & L. 561, 562 (2007).

<sup>33</sup> N.Y.C. DEP'T OF HEALTH & MENTAL HYGIENE, THE NEW YORK CITY A1C REGISTRY: SUPPORTING PROVIDERS & PATIENTS IN DIABETES CARE (2010), available at <http://home2.nyc.gov/html/doh/downloads/pdf/diabetes/diabetes-a1c-reg-serv.pdf>.

<sup>34</sup> Michelle M. Mello & Lawrence O. Gostin, Commentary, *A Legal Perspective on Diabetes Surveillance—Privacy and the Police Power*, 87 MILBANK Q. 575, 575 (2009).

<sup>35</sup> New York City's Health Code provides: “All clinical laboratories . . . shall electronically report to the Department all laboratory results for Hemoglobin A1C tests, as defined in subdivision (b) of this section, within 24 hours of obtaining such results.” N.Y.C., N.Y., HEALTH CODE tit. 24, § 13.07(a) (West 2012). New York defines “clinical laboratory” as “a facility, including a blood bank, regulated pursuant to [New York law] holding a permit

about each diabetic, including his or her name, date of birth, address, gender, medical record number, and any other identification code assigned to the patient, as well as the name and contact information of the diabetic's health care provider.<sup>36</sup> As of September 30, 2011, the A1C Registry contained over 9.4 million tests conducted on over 3.4 million people, approximately 1 million of whom were considered likely to have diabetes.<sup>37</sup> In New York City alone, as of 2004, there were approximately 500,000 people who had been diagnosed with diabetes and an estimated 200,000 who had diabetes but were not aware.<sup>38</sup> If the A1C Registry were expanded nationally, it could surveil the estimated 26 million Americans who have diabetes and 79 million with prediabetes.<sup>39</sup> Going forward, the CDC projects that roughly one third of the U.S. population could develop diabetes by 2050.<sup>40</sup>

Hemoglobin A1C tests measure a person's average blood sugar level over the preceding 90 days.<sup>41</sup> They are the *sine qua non* of diabetes management: They serve as a proxy for how "well-managed" a diabetic's blood sugar levels are.<sup>42</sup> A1C test results are strongly correlated with a person's risk level for diabetes-related complications, which include stroke, blindness, kidney failure, neuropathy, amputa-

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issued by the New York State Department of Health, and operating in the City or testing a specimen taken from a City resident." N.Y.C., N.Y., HEALTH CODE tit. 24, § 13.01 (West 2012).

<sup>36</sup> N.Y.C., N.Y., HEALTH CODE tit. 24, § 13.03(a) (West 2012) (requiring reporting of those categories of information, among others).

<sup>37</sup> N.Y.C. DEP'T OF HEALTH & MENTAL HYGIENE, NEW YORK CITY A1C REGISTRY: IMPROVING DIABETES CARE IN NEW YORK CITY 9 (2011) [hereinafter NEW YORK CITY A1C REGISTRY: IMPROVING DIABETES CARE IN NEW YORK CITY], available at <http://www.nyc.gov/html/doh/downloads/pdf/diabetes/diabetes-a1c-reg.pdf>.

<sup>38</sup> N.Y.C. DEP'T OF HEALTH & MENTAL HYGIENE, DIABETES IN NEW YORK CITY: PUBLIC HEALTH BURDEN AND DISPARITIES 1-1 (2006) [hereinafter DIABETES IN NEW YORK CITY: PUBLIC HEALTH BURDEN AND DISPARITIES], available at [http://www.nyc.gov/html/doh/downloads/pdf/epi/diabetes\\_chart\\_book.pdf](http://www.nyc.gov/html/doh/downloads/pdf/epi/diabetes_chart_book.pdf).

<sup>39</sup> Press Release, Ctrs. for Disease Control & Prevention, *supra* note 8.

<sup>40</sup> *Id.*

<sup>41</sup> See *The New York City A1C Registry*, N.Y.C. DEP'T OF HEALTH & MENTAL HYGIENE, <http://www.nyc.gov/html/doh/html/diabetes/diabetes-nycar.shtml> (last visited Aug. 19, 2012) ("A1C measures average blood sugar level over the past 3 months. A1C is used to monitor and change treatment plans for individuals with diabetes. . . . Good control of A1C can help prevent complications such as heart, eye, kidney, and nerve disease.").

<sup>42</sup> The 1994 Diabetes Control and Complications Study "conclusively showed that intensive therapy, aimed at maintaining glycemic levels as close to the nondiabetic range as possible . . . markedly reduced the onset and progression of diabetic retinopathy, nephropathy, and neuropathy." John M. Lachin et al., *The Hemoglobin Glycation Index Is Not an Independent Predictor of the Risk of Microvascular Complications in the Diabetes Control and Complications Trial*, 56 DIABETES 1913, 1913 (2007). Subsequent analysis has shown that blood sugar levels over time, as represented by A1C tests, are the "principal determinant of the risk of [diabetes] complications." *Id.*

tion, and retinopathy.<sup>43</sup> The primary goal of diabetes management is to “control” blood sugar levels and achieve “normal” A1C results.<sup>44</sup>

Hemoglobin A1C test results are deeply personal for reasons that most Americans would find obvious: They are medical information, which we generally regard as private,<sup>45</sup> and they contain sensitive information about a person’s risk level for costly and debilitating health complications. However, to a diabetic, A1C tests are also personal for a less obvious reason. A diabetic keeps his blood sugar in a narrow range by cumulative and mundane life choices. Food, exercise, adrenaline, stress, caffeine, alcohol, hydration, medication, and activities like showering and sexual intercourse all affect blood sugar levels.<sup>46</sup> If a diabetic’s A1C levels reflect high blood sugar over time, the explanation is almost assuredly personal—for example,

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<sup>43</sup> CTRS. FOR DISEASE CONTROL & PREVENTION, NATIONAL DIABETES FACT SHEET: 2011, at 1–10 (2011), *available at* [http://www.cdc.gov/diabetes/pubs/pdf/fndfs\\_2011.pdf](http://www.cdc.gov/diabetes/pubs/pdf/fndfs_2011.pdf); DIABETES IN NEW YORK CITY: PUBLIC HEALTH BURDEN AND DISPARITIES, *supra* note 38, at 5-2 (“Improving control of blood glucose levels reduces the risk of diabetes complications affecting the heart, eyes, kidneys and nerves.”).

<sup>44</sup> In a booklet created for diabetics, the CDC explains that “[i]t’s important to your health to control your blood glucose (also called blood sugar). Keeping your glucose level close to normal helps prevent or delay some diabetes problems, such as eye disease, kidney disease, and nerve damage.” CTRS. FOR DISEASE CONTROL & PREVENTION, TAKE CHARGE OF YOUR DIABETES 21 (4th ed. 2007), *available at* <http://www.cdc.gov/diabetes/pubs/pdf/tcyd.pdf>. In addition, the booklet explains that an A1C test “can sum up your diabetes control for the past few months” and that achieving A1C levels within a “normal” range is the goal of diabetes management. *Id.* at 23. The booklet further recommends: “If your A1C test results are high, work with your team to adjust your balance of food, physical activity, and diabetes medicine. When your A1C test result is near your goal, you’ll know you’ve balanced things well.” *Id.* at 24.

<sup>45</sup> *See, e.g.*, *United States v. Westinghouse*, 638 F.2d 570, 577 (3d Cir. 1980) (stating that individuals are ordinarily entitled to keep health information private); Jessica C. Wilson, Note, *Protecting Privacy Absent a Constitutional Right: A Plausible Solution to Safeguarding Medical Records*, 85 WASH. U. L. REV. 653, 655–56 (2007) (describing widely accepted views on the importance of medical privacy).

<sup>46</sup> *See, e.g.*, *Stress*, AM. DIABETES ASS’N, <http://www.diabetes.org/living-with-diabetes/complications/stress.html> (last visited Aug. 19, 2012) (describing the physiological mechanisms by which stress can elevate blood sugar levels in diabetics and citing examples of physical, mental, and emotional sources of stress that can affect blood sugar, including “problems in your marriage, job, health, or finances . . . taking a test . . . getting stuck in a traffic jam . . . working for a demanding boss [and] taking care of an aging parent”). *See also* Linda M. Delahanty & David K. McCulloch, *Patient Information: Type 2 Diabetes Mellitus and Diet (Beyond the Basics)*, UPTODATE, <http://www.uptodate.com/contents/type-2-diabetes-mellitus-and-diet-beyond-the-basics> (last visited Oct. 1, 2012) (explaining that most factors that determine successful diabetes management are “controlled by the person with diabetes, including how much and what is eaten, how frequently the blood sugar is monitored, physical activity levels, and accuracy and consistency of medication dosing” and that even “small changes” in diet affect blood sugar control). *See also* *Diabetes and Sex*, DIABETES.CO.UK, <http://www.diabetes.co.uk/diabetes-and-sex.html> (last visited Oct. 14, 2012) (explaining that sexual intercourse can cause hypoglycemia, or dangerously low blood sugar).

circumstances that make lifestyle modifications a secondary priority: the stress of a new job, food addiction, or denial about the risks associated with diabetes.

The nature of A1C test results is important for three reasons. First, it suggests that the A1C Registry constitutes continual surveillance not only because it aims to collect A1C test results for the lifetime of each diabetic, but also because each test result describes a diabetic's continuous physical state. Second, it demonstrates several reasons that the surveillance at issue in emergent programs effects a particularly intimate privacy invasion. Blood sugar fluctuations are not just "medical information": They are the product of a huge array of a diabetic's personal behaviors. A similar claim could be made with respect to measures used to track obesity and obesity-related health conditions. Third, because the primary "inputs" to the A1C test *are* personal behaviors, government attempts to improve A1C results are likely to be less effective than their predecessors, which targeted communicable disease or exposure-related health risks.<sup>47</sup>

In addition to surveillance, the A1C Registry program includes two interventions. Adult diabetics with high A1C test results and patients who are overdue for an A1C test receive letters from the Department.<sup>48</sup> The Department also sends quarterly reports to health care providers identifying patients "at higher risk for diabetes-related complications."<sup>49</sup> The reports compare the at-risk individuals' glycemic control (as measured by the A1C) to city benchmarks.<sup>50</sup> However, the program "offers no increased resources for diabetes treatment or services" and it neither "identif[ies] nor address[es] the needs of people who lack any access to health care."<sup>51</sup> Diabetics can request that the Department not contact them or their health providers, but—crucially—they cannot prevent labs from sending their A1C results and personal information to the Department, nor can

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<sup>47</sup> This argument is developed further in Part III.B, which explains that because preventing and managing diabetes require significant and lifetime behavioral changes, government public health interventions are likely to be less effective than are government interventions that aim to prevent the spread of infectious or exposure-related diseases.

<sup>48</sup> See, e.g., *NEW YORK CITY A1C REGISTRY: IMPROVING DIABETES CARE IN NEW YORK CITY*, *supra* note 37, at 22 (providing a sample letter informing patients with high A1C test results that (i) their A1C is "too high," (ii) lowering their A1C can reduce the risk of heart, kidney, eye, and foot problems, and (iii) they should either find a doctor, or ask their present doctor about medications, food choices, and exercise).

<sup>49</sup> *Id.* at 5.

<sup>50</sup> *Id.*

<sup>51</sup> Janlori Goldman et al., *New York City's Initiatives on Diabetes and HIV/AIDS: Implications for Patient Care, Public Health, and Medical Professionalism*, 98 *AM. J. PUB. HEALTH* 807, 809 (2008).

they prevent the Department from retaining and using the information.<sup>52</sup>

## 2. Proliferation of the Model

New York City's A1C Registry is the prototype of what I call the "emergent" model of public health surveillance. Supporters and critics of the A1C Registry agree on two things: that the surveillance model differs significantly from its predecessors, and that governments are likely to replicate it. Commentators explain that by initiating "ongoing, systematic diabetes surveillance for an entire population,"<sup>53</sup> the A1C Registry has "mov[ed] the city to the vanguard of chronic-disease management."<sup>54</sup> Commentators agree that the A1C Registry is "a harbinger of a trend in which the government will apply tactics traditionally reserved primarily for infectious diseases to chronic conditions."<sup>55</sup> Amy L. Fairchild explains that "[i]f New York City [serves] as a model, public health surveillance in the United States will take on a radical new form."<sup>56</sup>

There are several indications that programs like the A1C Registry will proliferate. For example, Dr. Paul Simon of Los Angeles County's Public Health Department has predicted that other U.S. cities would likely replicate the A1C Registry.<sup>57</sup> Like diabetes, obesity has widely been described as an "epidemic," a "crisis," and a leading cause of inflating health care costs.<sup>58</sup> Public health experts have identified "tackling" obesity and "lifestyle- and behavior-induced diseases" as a top priority for health care reform in the United States.<sup>59</sup> Some

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<sup>52</sup> See, e.g., *id.* at 809 ("Inclusion in the registry is mandatory—neither patients nor physicians can opt out."). To avoid receiving communications from the Department, a diabetic must submit a "Do Not Contact" request form each time he changes his address or phone number. Wilson, *supra* note 45, at 655. The form is on the Department website, but many patients are not aware it exists. *Id.* at 655 n.20.

<sup>53</sup> Amy L. Fairchild, *Diabetes and Disease Surveillance*, 313 *SCIENCE* 175, 175 (2006).

<sup>54</sup> Fairchild & Alkon, *supra* note 32, at 562.

<sup>55</sup> Rob Stein, *New York City Starts to Monitor Diabetics*, *WASH. POST*, Jan. 11, 2006, at A03. See also Goldman et al., *supra* note 51, at 807 ("It is no exaggeration to say that public health policy is at a crossroads and that the events in New York may be a harbinger of a national trend.")

<sup>56</sup> Fairchild, *supra* note 53, at 175.

<sup>57</sup> Associated Press, *New York May Begin Tracking Diabetes Patients*, *NBCNEWS.COM* (July 25, 2005), <http://www.msnbc.msn.com/id/8702244/#.T0FPu5j3C2w>.

<sup>58</sup> *Food For Thought: How to Improve Child Nutrition Programs: Hearing Before the Subcomm. on Educ. Reform of the H. Comm. on Educ. & the Workforce*, 108th Cong. 7 (2003) (statement of Richard H. Carmona, Surgeon General of the United States) ("The crisis is obesity. It's the fastest-growing cause of disease and death in America. . . . [T]he fact is that we [also] have an epidemic of childhood obesity.")

<sup>59</sup> Paul D. Mango & Vivian E. Riefberg, *Three Imperatives for Improving US Health Care*, *MCKINSEY Q.*, Dec. 2008, at 1, 3.

states and public school districts have recently started to monitor public school students' body size.<sup>60</sup> In addition, President Barack Obama appointed the architect of the A1C Registry, Dr. Thomas R. Frieden, as Director of the Centers for Disease Control and Prevention; in the White House press release announcing the appointment, the President stated that Dr. Frieden had been "at the forefront" of the fight against serious diseases, including obesity.<sup>61</sup>

Emergent public health surveillance means: (i) conducting non-consensual, ongoing, and intimate surveillance of a large number of people because they have a noncommunicable health condition and (ii) maintaining individually-identified databases of the information gathered. Emergent public health surveillance creates the potential to intervene directly in the lives and/or medical care of patients with chronic conditions. In its current incarnation as the A1C Registry, emergent surveillance is justified as a necessary response to crisis, which is found by analogizing diabetes to an infectious epidemic or by citing the financial impact of diabetes-related complications.<sup>62</sup>

The emergent model brings to the fore questions about the constitutional permissibility of the privacy invasion at the core of public health surveillance programs. In Part II, I describe existing constitutional privacy protections for medical and other personal information. I argue that emergent public health surveillance programs—unlike their predecessors and unlike alternative surveillance models—invade a fundamental privacy interest and should accordingly receive strict scrutiny under the Fourteenth Amendment. My argument is limited to the privacy invasion effected by the government's ongoing and non-consensual collection of individually-identified health information, like A1C results. I do not address the privacy implications of individually-targeted health interventions.<sup>63</sup>

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<sup>60</sup> See, e.g., 2003 Ark. Acts. 1220 § 6–17–119 (a)–(f) (mandating Body Mass Index (BMI) information to be included in report cards and prohibiting access to in-school vending machines); see also UNIV. OF ARK. FOR MED. SCI., YEAR FOUR EVALUATION: ARK. ACT 1220 OF 2003 TO COMBAT CHILDHOOD OBESITY 5, 7 (2008), available at <http://www.uams.edu/coph/childhoodobesity/COPH%20Obesity%20Evaluation%20Report%204.pdf> (evaluating results of the 2003 legislation).

<sup>61</sup> Press Release, The White House Office of the Press Sec'y, President Obama Appoints Dr. Thomas Frieden as CDC Director (May 15, 2009), available at <http://www.whitehouse.gov/the-press-office/president-obama-appoints-dr-thomas-frieden-cdc-director>.

<sup>62</sup> See *infra* notes 212–14 and accompanying text (noting experts who refer to obesity as an epidemic with severe consequences that justify public action).

<sup>63</sup> Other commentators have addressed the potential for interventions created by emergent public health surveillance programs. See, e.g., Amy L. Fairchild, Commentary, *Beyond Historical Precedent*, 87 MILBANK Q. 571, 571–73 (2009) (arguing that the "true import" of the A1C Registry is that it enables the New York City Department of Health to "manage clinical disease directly"); Lawrence O. Gostin, *Law as a Tool to Facilitate Healthier Lifestyles and Prevent Obesity*, 297 J. AM. MED. SCI. 87 (2007) (summarizing eight legal

## II EMERGENT PUBLIC HEALTH SURVEILLANCE INTRUDES UPON A FUNDAMENTAL INTEREST

Emergent public health surveillance programs intrude upon a privacy interest that courts should recognize as fundamental for purposes of the Fourteenth Amendment. Accordingly, emergent programs should be reviewed under a strict scrutiny standard.<sup>64</sup> The Supreme Court has recognized that the Fourteenth Amendment protects an interest in not disclosing private health information to the government.<sup>65</sup> However, the Supreme Court has never explained the contours of that right.<sup>66</sup> Moreover, lower court opinions that address the constitutionality of government public health surveillance programs are sparse, outdated, and inconsistent. In general, they have upheld public health surveillance programs against privacy challenges, after applying rational basis review or a deferential balancing test.<sup>67</sup>

Courts need not and should not apply a deferential standard to emergent programs. In Subpart A, I argue that existing jurisprudence does not require deferential review; in fact, it implicitly and explicitly

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“tools” that should be used to control obesity, including surveillance). Steven Lazarus, a New York City diabetic with a Master’s Degree in Public Health, testified in 2005: “[I]t appears that this law gives carte blanche to the Commissioner and staff in throwing different interventions against the wall and seeing what sticks.” N.Y.C. DEP’T OF HEALTH & MENTAL HYGIENE, NOTICE OF INTENTION TO AMEND ARTICLE 13 OF THE NEW YORK CITY HEALTH CODE AND PUBLIC HEARING 46 (2005) [hereinafter ARTICLE 13 PUBLIC HEARING] (statement of Dr. Steven Lazarus).

<sup>64</sup> See *infra* Part II.C (arguing that strict scrutiny should apply to emergent health programs because such programs intrude on an individual’s privacy interest, which is a fundamental right under the Fourteenth Amendment); see also David D. Meyer, *The Paradox of Family Privacy*, 53 VAND. L. REV. 527, 536–37 (2000) (explaining that “[t]raditional due process . . . provides that any state action that significantly impinges upon a fundamental right must be subjected to strict scrutiny, requiring the state to prove that its interference with the right is narrowly tailored to achieve a compelling state interest”).

<sup>65</sup> See *Whalen v. Roe*, 429 U.S. 589, 598–600 (1977) (explaining, in the context of a challenge to a public health surveillance program, that constitutional privacy protections “involve[] at least two different kinds of interests . . . [one of which is] the individual interest in avoiding disclosure of personal matters”).

<sup>66</sup> See *Wilson*, *supra* note 45, at 660–62 (explaining that *Whalen* “provided little guidance for lower courts dealing with medical privacy issues” and that the Supreme Court has only twice addressed the constitutional right to nondisclosure of personal information, both times affirming its existence without much elaboration or explanation).

<sup>67</sup> See *Mello & Gostin*, *supra* note 34, at 576 (“Legal challenges to public health reporting requirements typically fail . . . Courts explicitly hold that such interventions are within the police power, ruling that the state has a legitimate interest in avoiding the social and economic costs associated with health risk behaviors.”); see also Harold J. Krent et al., *Whose Business Is Your Pancreas? Potential Privacy Problems in New York City’s Mandatory Diabetes Registry*, 17 ANNALS HEALTH L. 1, 13 (2008) (stating that the only courts that have assessed the constitutionality of individually-identified state registries of health information have applied a “rational basis standard of review”).

invites more stringent review of emergent programs like the A1C Registry. In Subpart B, I suggest that, to the extent that the constitutionality of the privacy invasion effected by emergent public health surveillance programs remains an open question, recent assessments of security surveillance programs help to provide an answer. I describe three features of security surveillance that have provoked privacy concerns, and that either do or may increase the constitutional protections for privacy afforded under the Fourth Amendment. Because emergent health surveillance programs share those features, courts should similarly enhance the constitutional scrutiny that applies to those programs under the Fourteenth Amendment. In Subpart C, I summarize the argument for applying strict scrutiny to emergent programs.

### A. *Health Information Privacy Precedents*

This Subpart describes existing Fourteenth Amendment privacy protections that apply to government public health surveillance programs. Those protections are widely understood to be limited, and—to the extent the question has been addressed—scholars assume similarly limited protection would apply to emergent programs.<sup>68</sup> That assumption is unwarranted: The relevant precedents are inconsistent, outdated, and address readily distinguishable surveillance models. Moreover, several courts and judges have suggested that developments in public health surveillance could or should trigger more rigorous scrutiny.

The Supreme Court has recognized a “right of personal privacy” protected by the Due Process Clause of the Fourteenth Amendment.<sup>69</sup> In *Whalen v. Roe*, the Supreme Court recognized a privacy interest in medical information protected by the Fourteenth

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<sup>68</sup> See *infra* notes 76–77 and accompanying text (describing scholars’ understanding of the case law); see also Mello & Gostin, *supra* note 34, at 576 (citing *Whalen* to explain that “[t]he U.S. Supreme Court has recognized a limited constitutionally protected interest in health information privacy”).

<sup>69</sup> In *Roe v. Wade*, the Supreme Court reviewed its constitutional decisions concerning privacy, and stated that “a right of personal privacy, or a guarantee of certain areas or zones of privacy, does exist under the Constitution” and is “founded in the Fourteenth Amendment’s concept of personal liberty and restrictions upon state action.” 410 U.S. 113, 152–53 (1973). *Roe* established that the Fourteenth Amendment—and not other parts of the Constitution—is the primary source of protection for personal privacy. See, e.g., Anita L. Allen-Castellitto, *Understanding Privacy: The Basics*, in SEVENTH ANNUAL INSTITUTE ON PRIVACY LAW: EVOLVING LAWS AND PRACTICES IN A SECURITY-DRIVEN WORLD 23, 31 (2006) (“Increasingly after *Roe v. Wade* . . . the Fourteenth Amendment became the major legal tool for persons asserting controversial privacy rights against government.”).

Amendment,<sup>70</sup> and in *Nixon v. Administrator of General Services*, the Court affirmed the existence of a more general constitutionally protected interest in the nondisclosure of personal information.<sup>71</sup> The Supreme Court has not addressed the “constitutional right to informational privacy” since 1977.<sup>72</sup> Moreover, no federal court has addressed the constitutionality of government *registries* of health information since the 1970s.<sup>73</sup> To the extent that lower courts developed a coherent constitutional jurisprudence of medical privacy after *Whalen*,<sup>74</sup> they applied either a deferential balancing test or rational basis review to government programs that allegedly violated that right.<sup>75</sup> Most scholars assume that a deferential standard of review would similarly apply to emergent public health surveillance pro-

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<sup>70</sup> *Whalen v. Roe*, 429 U.S. 589, 598–600 & n.23 (1977) (citing *Roe v. Wade* and explaining that the privacy right is “founded in the Fourteenth Amendment’s concept of personal liberty” and that it protects “two different kinds of interests”—an interest in avoiding disclosure of personal information, and an interest in making certain decisions independently).

<sup>71</sup> *Nixon v. Adm’r of Gen. Servs.*, 433 U.S. 455–57 (1977) (explaining that public officials enjoy the “constitutionally protected privacy rights in matters of personal life” described in *Whalen*, despite having “voluntarily surrendered the privacy secured by law” for private citizens).

<sup>72</sup> *Nat’l Aeronautics & Space Admin. v. Nelson*, 131 S. Ct. 746, 756 (2011) (“Since [*Nixon v. Administrator of General Services* was decided in 1977], the Court has said little else on the subject of an ‘individual interest in avoiding disclosure of personal matters.’ . . . A few opinions have mentioned the concept in passing and in other contexts. . . . But no other decision has squarely addressed a constitutional right to informational privacy.” (quoting *Nixon*, 433 U.S. at 457; *Whalen*, 429 U.S. at 599)).

<sup>73</sup> Krent et al., *supra* note 67, at 13.

<sup>74</sup> See Wilson, *supra* note 45, at 660 (stating that, with respect to the private interest in not revealing personal information, *Whalen* “left unclear what constituted a violation of the right, and failed to establish what type of constitutional treatment the courts were to use when assessing it”); *id.* at 669 (identifying “twelve different interpretations” of *Whalen* in federal appellate cases); Jessica Ansley Bodger, Note, *Taking the Sting Out of Reporting Requirements: Reproductive Health Clinics and the Constitutional Right to Informational Privacy*, 56 DUKE L.J. 583, 599–600 (2006). Bodger explains that, after *Whalen*, the circuit courts of appeal “have split on whether the Constitution protects a constitutional right against the disclosure of private information, though the majority recognize some protection.” *Id.* at 599–600.

<sup>75</sup> See, e.g., *id.* at 599–601 (summarizing post-*Whalen* federal appellate case law on informational privacy, and explaining that most circuit courts of appeal recognize a limited constitutional right to informational privacy and apply a balancing test “to determine whether a state intrusion into personal information is warranted,” but that three circuits apply “rational basis review”).

grams.<sup>76</sup> One scholar who argues that the A1C Registry effects an unconstitutional privacy invasion makes the same assumption.<sup>77</sup>

*Whalen* is the only Supreme Court case that has addressed whether a public health surveillance program violated a constitutional right to privacy.<sup>78</sup> In *Whalen*, the Supreme Court upheld the New York State Controlled Substances Act of 1972, which authorized the New York State Department of Health to maintain a database of the names and addresses of all individuals who obtained Schedule II drugs pursuant to a doctor's prescription. The Court identified "at least two different kinds of interests" that fall within constitutional "privacy" protections: the individual "interest in avoiding disclosure of personal matters" and the "interest in independence in making certain kinds of important decisions."<sup>79</sup> The former is a constitutional right *not* to disclose personal information, including health information.<sup>80</sup> Emergent public health surveillance infringes upon this component of the constitutional right to privacy.<sup>81</sup>

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<sup>76</sup> See, e.g., Krent et al., *supra* note 67, at 14 (concluding that New York City's A1C Registry Program would survive a constitutional challenge because the statute meets a "rational basis" standard); cf. Wilson, *supra* note 45, at 674–75 (arguing that privacy tort law would provide better protection for confidential health records than the Fourteenth Amendment because of the "inconsistent and inadequate privacy protection" that pervades the constitutional analysis applied by courts).

<sup>77</sup> Cf. Wendy K. Mariner, *Medicine and Public Health: Crossing Legal Boundaries*, 10 J. HEALTH CARE L. & POL'Y 121, 149 (2007) (arguing that *Whalen* and other federal court opinions' emphasis on security measures in reporting programs does not meet the government's burden "to prove that requiring personally identifiable information is at least a rational means of achieving a legitimate state interest").

<sup>78</sup> See *Nat'l Aeronautics & Space Admin. v. Nelson*, 131 S. Ct. 746, 756 (2011) (stating that since *Nixon*, which concerned privacy for public officials, and *Whalen* were decided in 1977, "no other decision has squarely addressed a constitutional right to informational privacy").

<sup>79</sup> *Whalen v. Roe*, 429 U.S. 589, 599–600 (1977). Jurists and scholars refer to these interests as the right to confidentiality and the right to autonomy. See Wilson, *supra* note 45, at 661–62 (explaining that, since *Whalen*, judicial opinions interpreting its holding refer to the "'individual interest in avoiding disclosure of personal matters' as the right to confidentiality" and that *Whalen*'s "'independence in making certain kinds of decisions' has been termed the right to autonomy" (citing *Borucki v. Ryan*, 827 F.2d 836, 840 (1st Cir. 1987))).

<sup>80</sup> See, e.g., *Doe v. City of New York*, 15 F.3d 264, 266–67 (2d Cir. 1994) (holding that, under *Whalen*, there is a "recognized constitutional right to privacy in personal information" and that "[e]xtension of the right to confidentiality to personal medical information recognizes there are few matters that are quite so personal as the status of one's health, and few matters the dissemination of which one would prefer to maintain greater control over").

<sup>81</sup> See *infra* Part III (arguing that the A1C Registry and similar programs may effect an unconstitutional invasion of privacy under a strict scrutiny analysis because they do not effectively improve patient health). While outside the scope of this Note, surveillance-based *interventions* in the medical treatment or lifestyle choices of people with diabetes, obesity, or other non-communicable health conditions may infringe upon the right to deci-

In *United States v. Westinghouse Electric Corp.*, the Third Circuit created a deferential balancing test to determine the constitutionality of government intrusions into medical privacy,<sup>82</sup> which has been uniquely influential in medical privacy scholarship and jurisprudence.<sup>83</sup> *Westinghouse* involved an investigation by the National Institute for Occupational Safety and Health (NIOSH) into possible worker exposure to chemicals at an electrical plant.<sup>84</sup> The Third Circuit held that Westinghouse had to comply with a NIOSH subpoena for employee medical records, but it required NIOSH to permit each employee whose medical records it sought to raise a personal claim of privacy in the district court.<sup>85</sup> The Third Circuit created a seven-factor test,<sup>86</sup> and a number of other circuit courts of appeals have followed *Westinghouse* by applying a balancing test. However, most have applied either a subset of the *Westinghouse* factors or different factors.<sup>87</sup>

The assumption that a deferential standard of review would apply to emergent public health surveillance programs is unwarranted for at least two reasons. First, the programs at issue in *Whalen*, *Westinghouse*, and other cases that have applied a deferential standard differ in fundamental respects from emergent public health

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sional autonomy also recognized in *Whalen*. In addition, if a public health surveillance program subjected a targeted population to *mandatory* testing (rather than collecting tests ordered by health care providers), the Fourth Amendment would probably apply. In *Ferguson v. City of Charleston*, the Supreme Court explained that “we have routinely treated urine screens taken by state agents as searches within the meaning of the Fourth Amendment,” regardless of whether the results were reported to law enforcement authorities. 532 U.S. 67, 76 n.9 (2000).

<sup>82</sup> 638 F.2d 570 (3d Cir. 1980).

<sup>83</sup> See, e.g., Mello & Gostin, *supra* note 34, at 576–77 (applying the *Westinghouse* factors to conclude that the A1C Registry is constitutional); Wilson, *supra* note 45, at 662 (“The seminal circuit court case affirming the constitutional right to confidentiality is the Third Circuit’s decision in *United States v. Westinghouse Electric Corp.*”); Bodger, *supra* note 74, at 601 (“[T]he clearest elucidation of the factors to consider [when determining the constitutionality of informational privacy violations] came from the Third Circuit . . . in *United States v. Westinghouse Electric Corp.*”).

<sup>84</sup> *Westinghouse*, 638 F.2d at 572. NIOSH issued a subpoena for the medical records of all employees who worked in the affected area, and subsequently filed an action against Westinghouse when the latter refused to comply. *Id.* at 573.

<sup>85</sup> *Id.* at 580–82.

<sup>86</sup> *Id.* at 578.

The factors which should be considered . . . are the type of record requested, the information it might contain, the potential for harm in any subsequent non-consensual disclosure, the injury from disclosure to the relationship in which the record was generated, the adequacy of safeguards to prevent unauthorized disclosure, the need for access, and whether there is an express statutory mandate, public policy, or other recognizable public interest requiring access. *Id.*

<sup>87</sup> See Wilson, *supra* note 45, at 663–69 (summarizing variations on the *Westinghouse* balancing test).

surveillance programs like the A1C Registry. The Schedule II prescriptions registry at issue in *Whalen* targeted only “prescriptions for certain drugs with a high potential for abuse,”<sup>88</sup> an activity that the State could have prohibited entirely.<sup>89</sup> The program was primarily a law enforcement initiative, and the information gathered was needed for one of its law enforcement objectives: identifying and stopping participants in the illicit market for Schedule II drugs.<sup>90</sup> In addition, the program did not effect a wholly novel incursion into medical privacy. It was modeled on similar programs in two other states,<sup>91</sup> and it systematized a long-standing and unchallenged New York State requirement that doctors provide the State with the same information upon request.<sup>92</sup> *Westinghouse* involved a government investigation into a suspected, ongoing toxic exposure at a single facility; moreover, NIOSH investigated at the request of the plant workers whose medical privacy was threatened.<sup>93</sup>

Second, the medical privacy precedents intimate that developments in government surveillance that increase or alter the privacy invasion at issue could change the constitutional analysis. The *Whalen* Court limited its holding to the New York Controlled Substances Act of 1972, in part because of the “threat to privacy implicit in the accumulation of vast amounts of personal information in computerized data banks or other massive government files.”<sup>94</sup> In his concurring opinion in *Whalen*, Justice Brennan explained that “the Constitution puts limits not only on the type of information the State may gather, but also on the means it may use to gather it.”<sup>95</sup> Justice Brennan found “troubling” the “central storage and easy accessibility of computerized data,” and he was “not prepared to say that future

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<sup>88</sup> *Whalen v. Roe*, 429 U.S. 589, 606 (1977) (Brennan, J., concurring).

<sup>89</sup> *Id.* at 603 (“[T]he State no doubt could prohibit entirely the use of particular Schedule II drugs . . .”); *id.* at 603 n.30 (“It is, of course, well settled that the State has broad police powers in regulating the administration of drugs by the health professions.”).

<sup>90</sup> *Id.* at 592 n.6 (“Law enforcement officials in both California and Illinois . . . [inform us that similar programs] are not only a useful adjunct to the proper identification of culpable professional and unscrupulous drug abusers, but that they also give a reliable statistical indication of the pattern of drug flow throughout their states . . .”).

<sup>91</sup> *Id.* at 592 (“In drafting [the legislation at issue], the [New York State] commission consulted with enforcement officials in California and Illinois where central reporting systems were being used effectively.”).

<sup>92</sup> *Id.* at 606 (Brennan, J., concurring) (“As the record makes clear, New York has long required doctors to make this information available to its officials on request, and that practice is not challenged here.”).

<sup>93</sup> *United States v. Westinghouse*, 638 F.2d 570, 572 (3d Cir. 1980).

<sup>94</sup> *Whalen*, 429 U.S. at 605.

<sup>95</sup> *Id.* at 607 (Brennan, J., concurring).

developments will not demonstrate the necessity of some curb on such technology.”<sup>96</sup>

Similarly, in a 1975 opinion upholding a New York City registry of pregnancy terminations (a newly legalized practice), the New York Court of Appeals expressed concern about the prospective risks of privacy invasion from “modern computer technology.”<sup>97</sup> The court explained that “computerized information storage and retrieval systems may pose a significant threat to the constitutionally protected right to privacy,” and that the risk was highest “when governmental entities are permitted to indiscriminately seek and compile information concerning individuals for . . . vaguely articulated reasons.”<sup>98</sup>

The *Westinghouse* court recognized that medical information “may contain intimate facts of a personal nature” and that “[i]nformation about one’s body and state of health is matter which the individual is ordinarily entitled to retain within the ‘private enclave where he may lead a private life.’”<sup>99</sup> It held that the strong public interest in the NIOSH investigation justified NIOSH’s subpoena,<sup>100</sup> but it simultaneously required NIOSH to permit employees to raise personal privacy claims because some employee medical files might contain “highly sensitive” information in addition to routine, employment-related information.<sup>101</sup> In addition, the *Westinghouse* majority—like the *Whalen* majority—noted growing judicial and public concern with “governmental accumulation of data” and with “the ability of government officials to put information technology to uses detrimental to individual privacy which have been facilitated by the spread of data banks and by the increasing storage in computers of sensitive information relating to the personal lives and activities of private citizens.”<sup>102</sup>

Courts have not considered the implications for Fourteenth Amendment privacy protections of the last thirty-five years of developments in public health surveillance programs, technology, or data mining capabilities. As a result, important questions remain unanswered: Does the fact that modern technology permits ongoing and intimate surveillance of personal behaviors alter the scope or nature of constitutional privacy protections in the context of public health

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<sup>96</sup> *Id.* at 606–07 (Brennan, J., concurring).

<sup>97</sup> *Schulman v. N.Y.C. Health & Hosps. Corp.*, 342 N.E.2d 501, 507 (N.Y. 1975).

<sup>98</sup> *Id.*

<sup>99</sup> *United States v. Westinghouse*, 638 F.2d 570, 577 (3d Cir. 1980).

<sup>100</sup> *Id.* at 580.

<sup>101</sup> *Id.* at 580–81.

<sup>102</sup> *Id.* at 576.

surveillance?<sup>103</sup> What about the fact that politically underrepresented populations disproportionately experience chronic diseases and obesity, and are therefore more likely to be targets of surveillance?<sup>104</sup>

*B. Similarities in Security Surveillance and Public Health Surveillance*

Courts and commentators have addressed similar questions in the context of security surveillance programs. In particular, they have identified three features of government security surveillance that make the privacy invasions especially troubling: the surveillance is increasingly comprehensive and intimate, it involves registries of unprecedented size and data mining potential, and it targets politically underrepresented domestic communities. In the context of security surveillance programs, all three features have provoked significant privacy concerns. However, there is variation in the extent to which courts have incorporated each concern into Fourth Amendment analysis: The intimate and comprehensive nature of government surveillance is changing the analysis under the Fourth Amendment and its state counterparts, the targeting of politically underrepresented communities has not explicitly done so, and the use of registries and data mining falls in the middle.

My goal in this Part is to borrow from recent judicial opinions and public commentary about each feature of security surveillance, and to suggest that emergent public health surveillance programs raise similar concerns.<sup>105</sup> I do not intend to equate Fourth Amendment doctrine with Fourteenth Amendment doctrine. I claim only that the Fourth Amendment cases demonstrate a growing judicial recognition that a relationship exists between government surveillance technologies and methods on the one hand, and the nature of the individual

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<sup>103</sup> See *infra* Parts II.B.1–2 (describing how changes in technology have affected Fourth Amendment jurisprudence and describing similarities between security surveillance and emergent public health programs).

<sup>104</sup> See *infra* Part II.B.3 (noting criticism of security surveillance programs that target underrepresented communities and pointing out that emergent public health programs also target underrepresented populations).

<sup>105</sup> The connection between public health surveillance and national security is not purely analogical. As the U.S. government institutionalized public health surveillance in the 1960s, practitioners intentionally used the term “epidemiologic” to distinguish it from military intelligence activities. Thacker, *supra* note 3, at 5. The attacks of September 11, 2001 prompted an expansion in public health agendas and budgets. Goldman et al., *supra* note 51, at 807. The attacks also “created a demand in the United States for real-time data transmission from the physician’s office to the response arm of public health.” Stephen B. Thacker & Jeffrey P. Koplan, *Foreword* to *MONITORING THE HEALTH OF POPULATIONS: STATISTICAL PRINCIPLES AND METHODS FOR PUBLIC HEALTH SURVEILLANCE*, at v (Rob Brookmeyer & Donna F. Stroup eds., 2004).

privacy interest at stake on the other. Similarly, I do not claim that the government interventions that may result from surveillance are the same in the security and public health surveillance contexts.<sup>106</sup> My claim is that emerging conclusions about the relationship between the nature of government surveillance and the privacy interest at stake in the security context can inform a conversation about emergent health programs. The security surveillance cases and commentary delineate an area of privacy—or alternatively, a type of government intrusion into personal privacy—that may warrant heightened constitutional protection. The analysis in this Part has two implications. First, emergent programs may effect a privacy invasion that violates social and constitutional values.<sup>107</sup> Second, altering constitutional jurisprudence in response to the changing nature of government surveillance activities is viable and appropriate. To oversimplify, if developments in security surveillance tactics and technologies can transform a permissible government activity into a “search” under the Fourth Amendment, which in turn requires *ex ante* judicial review before the activity can constitutionally occur, then similar developments in emergent public health surveillance programs may warrant more robust analysis under the Fourteenth Amendment.

### 1. *Comprehensive and Intimate Surveillance*

A series of recent judicial opinions hold that, in the context of criminal law enforcement, the government’s use of advanced technology can turn a permissible surveillance activity into a “search” under the Fourth Amendment of the Constitution (or its state counterparts), departing from earlier Supreme Court cases that held the opposite.<sup>108</sup> Taken together, the opinions indicate that using advanced

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<sup>106</sup> That said, this Note focuses only on the “harm” of the privacy invasion arising from government surveillance and not on the “harm” of the interventions that may follow. So limited, the harm of government surveillance *is* similar in security and public health contexts. Moreover, in the Fourth Amendment cases discussed, courts are concerned with the privacy rights of the individuals surveilled and not with the risk or nature of future government interventions.

<sup>107</sup> This claim is based largely on the public’s responses to the three features of government surveillance described in this Part. Those responses may reflect judicial and public beliefs about the scope of liberty that would be relevant to a substantive due process analysis. *See, e.g.*, *Lawrence v. Texas*, 539 U.S. 558, 571–72, 578 (2003) (explaining the unique relevance of “emerging awareness” about the parameters of personal liberty to its holding that there is a substantive due process right to engage in consensual, adult homosexual sex); *see also* Barry Friedman & Sara Solow, *The Federal Right to an Adequate Education*, 80 GEO. WASH. L. REV. (forthcoming 2012) (manuscript at 31–38) (describing the role of evolving practices in Supreme Court substantive due process cases).

<sup>108</sup> In *United States v. Knotts*, the Supreme Court held that planting a beeper in a container being transported by a criminal suspect in order to monitor his movements on public roads did not amount to a search or seizure under the Fourth Amendment. 460 U.S.

technology may alter the constitutional permissibility of surveillance activities for several reasons: (i) certain types of surveillance technology give a uniquely intimate view of an individual, (ii) there are virtually no limits on the government's potential or actual use of that technology, so the breadth of surveillance (how many people are targeted) and the depth (to what extent) are relatively unconstrained, and (iii) ongoing technological developments may further invade privacy.

Recent cases from the Supreme Court, the D.C. Circuit, and at least three state supreme courts have held that the use of certain surveillance technologies constitutes a search or a seizure under the Fourth Amendment. For example, several recent federal<sup>109</sup> and state<sup>110</sup> cases hold that placing GPS technology on a criminal suspect's vehicle to track his public movements over time constitutes an unreasonable search under the Fourth Amendment or its state counterparts.

One reason that the government's use of GPS technology to track public movements troubles courts is that it enables something approaching continuous surveillance of a large number of people. The New York Court of Appeals explained in 2009 that "[i]t is quite clear that [tracking a person's public movements] . . . realistically could not

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276, 285 (1983). The Court explained that the surveillance was permissible because "[n]othing in the Fourth Amendment prohibited the police from augmenting the sensory faculties bestowed upon them at birth with such enhancement as science and technology afforded them in this case." *Id.* at 282. The more recent cases discussed in this Part address technology that "augments" to a far greater degree the sensory faculties and surveillance capabilities of government agents, but conclude that the surveillance *is* a search or seizure under the Fourth Amendment.

<sup>109</sup> In *United States v. Jones*, 132 S. Ct. 945, 949 (2012), the Supreme Court upheld the D.C. Circuit's decision in *United States v. Maynard*, 615 F.3d 544 (D.C. Cir. 2010), but only on the ground that placing the GPS technology on the suspect's car was a physical trespass that constituted a search for the purposes of the Fourth Amendment. Two concurring opinions in *Jones* emphasized concerns about surveillance technology similar to those identified by the D.C. Circuit. See *Jones*, 132 S. Ct. at 954 (Sotomayor, J., concurring); *id.* at 957 (Alito, J., concurring); see also *infra* note 120 and accompanying text (describing Justice Sotomayor's concurrence).

<sup>110</sup> At least three state supreme courts have held that, under their state constitutions' counterparts to the Fourth Amendment, law enforcement officials cannot place tracking devices on suspects' vehicles without first getting a warrant. In *People v. Weaver*, the New York Court of Appeals held that the New York State Police violated Art. I, § 12 of the New York Constitution when, without a warrant, they placed a GPS tracking device inside the bumper of a suspect's van and tracked his public movements for sixty-five days. 909 N.E.2d 1195, 1203 (N.Y. 2009). Similarly, in 2003, the Supreme Court of Washington, sitting en banc, held that Art. I, § 7 of the Washington Constitution requires police to get a warrant before installing GPS tracking technology on a suspect's car. *State v. Jackson*, 76 P.3d 217, 224 (Wash. 2003) (en banc). The Supreme Court of Oregon held in 1988 that attaching a radio transmitter to a suspect's car and using it to locate that car constituted a "search" and a "seizure" under Art. I, § 9 of the Oregon Constitution, and therefore required a warrant. *State v. Campbell*, 759 P.2d 1040, 1041 (Or. 1988).

have been done without GPS and that this dragnet use of the technology at the sole discretion of [the government] to pry into the details of people's daily lives is not consistent with the values at the core of [the state constitution]."<sup>111</sup> Invoking the "mosaic theory" often used by the government to deny requests for information related to national security,<sup>112</sup> the D.C. Circuit in *Maynard* explained that "[p]rolonged surveillance reveals types of information not revealed by short-term surveillance . . . [which] can . . . reveal more about a person than does any individual trip viewed in isolation."<sup>113</sup> In other words, gathering a sufficient number of data points about an individual effects a constitutionally significant privacy invasion, even if gathering fewer data points does not.

Isolated acts of government surveillance that target uniquely intimate spheres of personal life can also trigger Fourth Amendment privacy protections. In *Kyllo v. United States*,<sup>114</sup> the Supreme Court held that the government's use of thermal imaging technology aimed at a private home by law enforcement officials standing on a public street constituted a search because it effected an intimate invasion of an individual's home.<sup>115</sup> The *Kyllo* majority's concern derived in part from the uniquely strong Fourth Amendment protections accorded to the home,<sup>116</sup> but the Court emphasized that the central question was "what limits there are upon this power of technology to shrink the realm of guaranteed privacy."<sup>117</sup> The Court emphatically rejected the dissent's contention that there was no intimate invasion because the technology detected only waves emanating from the exterior of a

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<sup>111</sup> *Weaver*, 909 N.E.2d at 1203.

<sup>112</sup> The term "mosaic theory" refers to a "basic precept" of government security surveillance: "Disparate items of information, though individually of limited or no utility to their possessor, can take on added significance when combined with other items of information." David E. Pozen, Note, *The Mosaic Theory, National Security, and the Freedom of Information Act*, 115 *YALE L.J.* 628, 630 (2005). Since the September 11, 2001 attacks, the federal government has denied requests for information by invoking the mosaic theory, instead of proffering evidence that disclosing the information creates a likelihood of harm, and multiple circuit courts of appeals have relied on the theory to affirm government refusals to disclose information. *Id.* at 631.

<sup>113</sup> *Maynard*, 615 F.3d at 562.

<sup>114</sup> 533 U.S. 27 (2001).

<sup>115</sup> *Id.* at 40 ("Where, as here, the Government uses a device that is not in general public use, to explore details of the home that would previously have been unknowable without physical intrusion, the surveillance is a 'search' and is presumptively unreasonable without a warrant.").

<sup>116</sup> *Id.* at 37 ("In the home, our cases show, *all* details are intimate details, because the entire area is held safe from prying government eyes."). For a critical history of the "paramount importance of constraining government search of the home" in constitutional law and scholarship, see Stephanie M. Stern, *The Inviolable Home: Housing Exceptionalism in the Fourth Amendment*, 95 *CORNELL L. REV.* 905, 906 (2010).

<sup>117</sup> *Kyllo*, 533 U.S. at 34.

home, explaining that such a formalistic approach “would leave the homeowner at the mercy of advancing technology.”<sup>118</sup> In addition, the Supreme Court explicitly stated that government surveillance *methods* could violate constitutional limits on privacy invasion under the Fourth Amendment.<sup>119</sup>

The second reason that certain surveillance methods have troubled courts is that virtually no logistical or cost constraints limit their use. For example, concurring in *Jones*, Justice Sotomayor argued that because GPS technology offers a low-cost way to gather, store, and analyze information indefinitely, GPS-based surveillance activities require judicial supervision.<sup>120</sup> The D.C. Circuit below similarly emphasized the absence of logistical constraints, explaining that because there is virtually no marginal cost of using GPS technology to conduct surveillance, that technology “occasion[s] a heretofore unknown type of intrusion into an ordinarily and hitherto private enclave” for “practical reasons” alone.<sup>121</sup>

Third, courts reviewing the privacy implications of government security surveillance under the Fourth Amendment have incorporated into their analysis a recognition that government surveillance technologies are developing. For example, the *Kyllo* majority explained that “[w]hile the technology used in the present case was relatively crude, the rule we adopt must take account of more sophisticated systems that are already in use or in development.”<sup>122</sup> The New York Court of Appeals explained that “[w]ithout judicial oversight, the use of [advancing surveillance technology] presents a significant and . . . unacceptable risk of abuse.”<sup>123</sup> The Washington Supreme Court

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<sup>118</sup> *Id.* at 35–36.

<sup>119</sup> *Id.* at 35 n.2 (“The fact that equivalent information could sometimes be obtained by other means does not make lawful the use of means that violate the Fourth Amendment.”).

<sup>120</sup> *United States v. Jones*, 132 S. Ct. 945, 955–56 (2012) (Sotomayor, J., concurring) (noting that “GPS monitoring generates a precise, comprehensive record of a person’s public movements that reflects a wealth of detail” and that “[t]he Government can store such records and efficiently mine them for information years into the future”). Justice Sotomayor found that: “The net result is that GPS monitoring [makes] available at a relatively low cost . . . a substantial quantum of intimate information about any person . . . .” *Id.* at 956 (Sotomayor, J., concurring). Therefore, “[i]n cases involving even short-term monitoring, [these] unique attributes of GPS surveillance relevant to the [Fourth Amendment] analysis will require particular attention.” *Id.* at 955 (Sotomayor, J., concurring).

<sup>121</sup> *United States v. Maynard*, 615 F.3d 544, 565 (D.C. Cir. 2010) (“[T]he marginal cost of an additional day—or week, or month—of GPS monitoring is effectively zero. Nor . . . is the fixed cost of installing a GPS device significant . . . . For these practical reasons . . . GPS technology has occasioned a heretofore unknown type of intrusion into an ordinarily and hitherto private enclave.”).

<sup>122</sup> *Kyllo v. United States*, 533 U.S. 27, 36 (2001).

<sup>123</sup> *People v. Weaver*, 909 N.E.2d 1195, 1203 (N.Y. 2009).

acknowledged the possibility that technological advances reduce reasonable expectations of privacy, but nonetheless held that there is a “[state constitutional] right to be free” from warrantless GPS surveillance because it found GPS technology to be a “particularly intrusive method of surveillance” that enables the acquisition of an “enormous amount of personal information about the citizen.”<sup>124</sup> Concurring in *Jones*, Justice Alito, joined by Justices Ginsburg, Breyer, and Kagan, explained that “[i]n the pre-computer age, the greatest protections of privacy were neither constitutional nor statutory, but practical.”<sup>125</sup> By contrast, GPS technology permits “longer term” monitoring which Justice Alito found to violate reasonable expectations of privacy under the Fourth Amendment.<sup>126</sup>

The A1C Registry surveillance techniques raise privacy concerns similar to those identified in the GPS cases and in *Kyllo*. Given that emergent public health programs have received virtually no judicial or scholarly attention, the concerns identified in the security context—and the fact that those concerns have altered the constitutional status of some government surveillance programs under the Fourth Amendment and its counterparts in state constitutions—are useful guideposts in determining the constitutional status of emergent public health surveillance programs like the A1C Registry.

Like GPS surveillance, A1C Registry surveillance is comprehensive. It appropriates, at low cost, medical technology—the A1C test—to acquire a view of the individual that is uniquely intimate, both because the data is highly sensitive health information and because, cumulatively, A1C tests tell a story about a person’s daily habits.<sup>127</sup> It may do so for the lifetimes of millions of diabetics. There are few practical limits on the scope of the surveillance, as the A1C Registry’s rapid growth demonstrates: Health providers and labs simply forward electronically stored medical information. In addition, diabetes technology is developing. For example, continuous glucose monitoring (CGM) systems permit diabetics to track their glucose levels continuously and to upload that information for analysis.<sup>128</sup> As with A1C and

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<sup>124</sup> *State v. Jackson*, 76 P.3d 217, 224 (Wash. 2003).

<sup>125</sup> *Jones*, 132 S. Ct. at 963 (Alito, J., concurring).

<sup>126</sup> *Id.* at 964.

<sup>127</sup> The Fourth Amendment provides special privacy protections to the home. *See, e.g.*, Stern, *supra* note 116, at 912 (“Homes have achieved iconic status in the modern Fourth Amendment, with judicial rhetoric elevating residential search to the apex of protection.”). However, it is interesting to consider whether a person’s daily habits deserve similarly heightened protection, especially in light of research suggesting that the spatial conception of privacy is at “odds with the psychological research and privacy literature.” *Id.* at 924.

<sup>128</sup> *See, e.g.*, NAT’L DIABETES INFO. CLEARINGHOUSE, U.S. DEP’T OF HEALTH, CONTINUOUS GLUCOSE MONITORING 2 (2008), available at <http://diabetes.niddk.nih.gov/>

GPS data, CGM data could be made available to public health agencies with minimal additional cost and few logistical impediments.

## 2. *Electronic Data Collection and Data Mining*

The government has exponentially expanded its data mining capabilities,<sup>129</sup> and its use of data mining techniques, over the last decade.<sup>130</sup> Its data mining activities are largely unregulated by legislation.<sup>131</sup> The use of data mining and data matching techniques in security surveillance has received considerable critical attention,<sup>132</sup> and it has prompted severe disagreements within the executive branch.<sup>133</sup> Two circuit courts of appeals have held that plaintiffs have standing to challenge government surveillance programs that allegedly involve dragnet data collection and data mining techniques.<sup>134</sup> The

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dm/pubs/glucosemonitor/Continuous\_Glucose\_Monitoring\_508.pdf (reporting that multiple CGM devices have been approved by the U.S. Food and Drug Administration (FDA) and are available to diabetics by prescription). These devices provide real-time measurements of glucose levels, with glucose levels displayed at five-minute or one-minute intervals; accompanying software downloads data “for tracking and analysis of patterns and trends.” *Id.* More sophisticated CGM devices are being developed and tested. *Id.*

<sup>129</sup> The federal government defines “data mining” as “the use of sophisticated data analysis tools to discover previously unknown, valid patterns and relationships in large data sets.” JEFFREY W. SEIFERT, CONG. RESEARCH SERV., DATA MINING AND HOMELAND SECURITY: AN OVERVIEW 1 (2006).

<sup>130</sup> Christopher Slobogin, *Government Data Mining and the Fourth Amendment*, 75 U. CHI. L. REV. 317, 317 (2008) (“[D]ata mining has expanded enormously over the past decade. Since at least the mid-1990s, the quantity of the world’s recorded data has doubled every year. At the same time, the computing power necessary to store, access, and analyze these data has increased geometrically, at increasingly cheaper cost.”).

<sup>131</sup> *See id.* at 328 (“[V]arious scattered statutes affect [government data mining], albeit not to any significant extent.”).

<sup>132</sup> *See, e.g., id.* at 324–26 (identifying costs of data mining techniques, including frequent false results, the self-perpetuating use of “invidious” and discriminatory profiling through algorithms, the pressure to centralize all data to facilitate efficient data mining, and the risk of hacking); *see also* Jack M. Balkin, *The Constitution in the National Surveillance State*, 93 MINN. L. REV. 1, 15–17 (2008) (identifying three “major dangers” to freedom created by national security surveillance and data analysis programs, including “powerful and effective . . . technologies of surveillance and analysis” that create pressure to bypass constitutional and procedural requirements).

<sup>133</sup> *See, e.g.,* Scott Shane & David Johnston, *Mining of Data Prompted Fight over U.S. Spying*, N.Y. TIMES, July 29, 2007, at A1 (“A 2004 dispute over the National Security Agency’s secret surveillance program that led top Justice Department officials to threaten resignation involved computer searches through massive electronic databases, according to current and former officials briefed on the program.”).

<sup>134</sup> *Jewel v. Nat’l Sec. Agency*, 673 F.3d 902, 905–06 (9th Cir. 2011) (holding that plaintiffs in a putative class action have standing to challenge an NSA program that allegedly conducted “dragnet collection” of AT&T subscribers’ domestic phone and internet communications); *Amnesty Int’l USA v. Clapper*, 638 F.3d 118, 122 (2d Cir. 2011) (holding that plaintiffs have standing to bring a facial challenge to Section 702 of the Foreign Intelligence Surveillance Act of 1978 (FISA), 50 U.S.C. § 1881a (Supp. 2011) (repealed 2012), based on the plaintiffs’ fear that the government would intercept sensitive international communica-

Second Circuit indicated that the importance of scrutinizing the surveillance and data mining program at issue factored into its standing analysis.<sup>135</sup>

The A1C Registry is an individually-identified electronic registry which is stratified by A1C level. The possibility of data mining the Registry presents an interesting array of privacy concerns.<sup>136</sup> Some data mining would be useful to public health planning, and it seems likely the Department would want to do it: For example, correlating A1C trends with public health interventions, health care providers, or government benefits could serve the Department's objective of developing "interventions to help providers and patients better manage diabetes."<sup>137</sup> Data mining possibilities—and the associated privacy risks—would expand significantly if the Registry were combined with other government databases that contain information about the same individuals, or if the A1C Registry were expanded to include additional health information, like CGM data. Given that leading public health experts have identified data mining as a crucial opportunity,<sup>138</sup>

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tions, and the costs associated with avoiding such interceptions). Commentators have suggested that the Second Circuit's standing decision in *Amnesty International* was "puzzling," noting that it created a "very easy" way for plaintiffs to challenge security surveillance programs. Orin Kerr, *Amnesty International USA v. Clapper and Standing to Challenge Secret Surveillance Regimes*, THE Volokh Conspiracy (Mar. 24, 2011 2:46 AM), <http://volokh.com/2011/03/24/amnesty-international-usa-v-clapper-and-standing-to-challenge-secret-surveillance-regimes/> ("[*Amnesty International*] offers a very easy way for plaintiffs to have Article III standing to challenge secret surveillance statutes. The opinion strikes me as puzzling, however, and it appears to be in conflict with other Courts of Appeals cases on standing to challenge surveillance regimes.").

<sup>135</sup> *Amnesty Int'l USA v. Clapper*, 667 F.3d 163, 172 (2d Cir. 2011) (denying the defendant's petition for a rehearing en banc). In denying the petition for a rehearing en banc, the Second Circuit noted that "[t]o reject the plaintiffs' arguments not because they lack merit, but because we refuse to hear them, runs a much graver risk than whatever invasion of plaintiffs' privacy might be occasioned by the surveillance [authorized by FISA § 702]" because "[i]t is the glory of our system that even our elected leaders must defend the legality of their conduct when challenged." *Id.*

<sup>136</sup> Hacking and unwarranted disclosure are two concerns. Both could facilitate insurance or employment discrimination and cause embarrassment. *See* Goldman et al., *supra* note 51, at 811 (describing effects of disclosure of health information in the HIV context). However, courts reviewing public health registries have generally dismissed concerns about unwarranted disclosures absent affirmative indications that unwarranted disclosures are likely to occur. *See, e.g.,* Whalen v. Roe, 429 U.S. 589, 601 (1977) (finding no evidence that surveillance program security measures were inadequate or poorly administered); Schulman v. N.Y.C. Health & Hosp. Corp., 342 N.E.2d 501, 507 (N.Y. 1975) (finding no evidence of unauthorized disclosures).

<sup>137</sup> N.Y.C. DEP'T OF HEALTH & MENTAL HYGIENE, A1C REGISTRY: FREQUENTLY ASKED QUESTIONS 1 (2012), available at <http://www.nyc.gov/html/doh/downloads/pdf/csi/diabeteskit-hcp-a1c-faq.pdf>.

<sup>138</sup> *See* Thacker & Koplan, *supra* note 105, at vi (explaining that the "presence of new kinds of data in unprecedented volume produces a demand for better analysis" and that a key public health challenge is how to "obtain and use information from new sources of

it seems likely that data mining capabilities will be explored in emergent public health surveillance programs. In that vein, the architects of the A1C Registry emphasized their need for comprehensive data.<sup>139</sup> Faced with a request from the American Diabetes Association that the Registry be consent based, proponents of the A1C Registry replied that “complete ascertainment of cases was essential” and that a consent-based program “would not be effective.”<sup>140</sup>

### 3. Targeting Politically Vulnerable Domestic Communities

Security surveillance programs that target politically vulnerable domestic communities for dragnet surveillance have prompted widespread concern in the last decade, although legal challenges to national security programs generally have not reached a decision on the merits.<sup>141</sup> For example, politicians and advocacy groups responded promptly to the revelation that New York City Police Department surveillance programs targeted Arab and Muslim communities in the Northeast.<sup>142</sup> Some politicians publicly declared that the programs were “disturbing” and said they would not have allowed such a

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surveillance data (e.g., law enforcement, medical examiners, managed care organizations, and environmental sources) and link it to public health programs”).

<sup>139</sup> See COLGROVE, *supra* note 3, at 248 (noting that, in response to privacy concerns raised by the American Diabetes Association and others, “[t]hose in charge of the registry insisted that obtaining [consent] . . . would lead to incomplete ascertainment that would compromise the registry’s ability to give an accurate picture of the problem”).

<sup>140</sup> Fairchild & Alkon, *Back to the Future*, *supra* note 32, at 571–75.

<sup>141</sup> The doctrines of standing and political questions, and the state secrets privilege, have often prevented them from doing so. See, e.g., Scott Michelman, *Who Can Sue over Government Surveillance?*, 57 UCLA L. REV. 71, 74 (2009) (arguing that standing doctrine stymies judicial oversight of domestic surveillance programs); Samuel J. Rascoff, *Establishing Official Islam? The Law and Strategy of Counter-Radicalization*, 64 STAN. L. REV. 125, 189 n.312 (2012) (“The political question doctrine supplies a perennial obstacle to legal challenges of official national security policies.”); Beth George, Note, *An Administrative Law Approach to Reforming the State Secrets Privilege*, 84 N.Y.U. L. REV. 1691, 1692 (2009) (“[U]se of the state secrets privilege has increased dramatically in the last twenty years . . . not only as a discovery rule but also as a motion to dismiss lawsuits entirely, even when a plaintiff may have had access to enough evidence to prove her case without the protected information.”).

<sup>142</sup> In 2011, the Associated Press published a series of reports about the New York City Police Department (NYPD) surveillance program. See, e.g., Matt Apuzzo & Adam Goldman, *NYPD Keeps Files on Muslims Who Change Their Names*, ASSOCIATED PRESS (Oct. 26, 2011), <http://www.ap.org/Content/AP-In-The-News/2011/NYPD-keeps-files-on-Muslims-who-change-their-names> (“Since August, an Associated Press investigation has revealed a vast NYPD intelligence-collecting effort targeting Muslims following the terror attacks of September 2001. Police have conducted surveillance of entire Muslim neighborhoods, chronicling daily life including where people eat, pray and get their hair cut.”). For more Associated Press reports describing the NYPD’s surveillance program, see *Highlights of AP’s Pulitzer Prize-winning Probe into NYPD Intelligence Operations*, ASSOCIATED PRESS, <http://www.ap.org/media-center/nypd/investigation> (last visited Sept. 10, 2012).

program if they had known about it.<sup>143</sup> Academics and academic institutions expressed similar concern and criticism.<sup>144</sup> Community leaders petitioned the New Jersey Attorney General to investigate a New Jersey–based surveillance program and give “a full accounting” of ongoing surveillance.<sup>145</sup>

In the context of security surveillance, one commentator advocates robust constitutional privacy protections because “legislative efforts to regulate surveillance may . . . insufficiently protect the privacy of certain politically unpopular minorities, like Muslim-Americans.”<sup>146</sup> Like Arab and Muslim Americans in the security surveillance context,<sup>147</sup> people with diabetes, obesity, and certain other chronic conditions are politically vulnerable in the health surveillance context. Diabetes “disproportionately affects black and Latino New Yorkers, [and] . . . those living in low-income households and neighborhoods,” both with respect to its prevalence and the rates and severity of related complications.<sup>148</sup> The same is true of obesity and obesity-related health problems.<sup>149</sup> In addition, many chronic conditions, including diabetes, are “often perceived as a self-inflicted problem among the elderly who are sedentary and obese.”<sup>150</sup> The argument that governments have “a legitimate interest in controlling

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<sup>143</sup> See *Governor Christie, Mayor Booker Criticize NYPD Surveillance Of Muslim Students*, NEW YORK1 NEWS (Feb. 22, 2012), [http://www.ny1.com/content/top\\_stories/156478/governor-christie—mayor-booker-criticize-nypd-surveillance-of-muslim-students](http://www.ny1.com/content/top_stories/156478/governor-christie—mayor-booker-criticize-nypd-surveillance-of-muslim-students) (quoting Newark Mayor Cory Booker and New Jersey Governor Chris Christie).

<sup>144</sup> See, e.g., Heather Haddon & Pervaiz Shallwani, *Rutgers Wants Probe of NYPD Surveillance*, WALL ST. J., Feb. 21, 2012, at A23 (reporting that Rutgers University issued a statement condemning surveillance based on a protected characteristic and requested investigation of the program); Chris Hawley & Matt Apuzzo, *NYPD Infiltration of Colleges Raises Privacy Fears*, WALL ST. J. (Oct. 11, 2011), <http://online.wsj.com/article/AP60bf36d52cb449658160f88464302aec.html> (reporting that faculty councils at CUNY and Brooklyn College issued statements expressing concern about the civil rights implications of NYPD surveillance of Muslim students, and that student groups and professors had called for investigations into the NYPD program).

<sup>145</sup> Samantha Henry, *NJ Muslims, Officials Discuss NYPD Surveillance*, THE GUARDIAN (Mar. 3, 2012), <http://www.guardian.co.uk/world/feedarticle/10253220>; see also Hawley & Apuzzo, *supra* note 144 (reporting that the New York City Council “demanded answers” from the NYPD Commissioner about its surveillance programs that targeted Muslim communities, and required him to justify and explain the program).

<sup>146</sup> Stephen Rushin, *The Judicial Response to Mass Police Surveillance*, 2011 U. ILL. J.L. TECH. & POL’Y 281, 323.

<sup>147</sup> *Id.* (“[I]n the current heated and divisive political environment, Muslim-Americans are the individuals most at risk of indiscriminate surveillance data collection and subsequent fishing expeditions.”).

<sup>148</sup> DIABETES IN NEW YORK CITY: PUBLIC HEALTH BURDEN AND DISPARITIES, *supra* note 38, at ES-1.

<sup>149</sup> See, e.g., Gostin, *supra* note 63, at 87 (“[N]onwhite and poor individuals experience a substantial disproportionate burden from obesity . . .”).

<sup>150</sup> Mariner, *supra* note 77, at 150–51.

medical and social costs of individuals' unhealthy behaviors that are borne by society at large"<sup>151</sup> may be used to justify inappropriate privacy invasions, especially given that public discourse about obesity is infused with moral condemnation.<sup>152</sup> Judicial recognition that emergent programs infringe upon constitutionally protected privacy rights would require governments to develop substantive (instead of rhetorical) justifications for deploying the most invasive types of public health surveillance against vulnerable populations or, alternatively, to modify those surveillance programs.

One indication that diabetics may be a politically vulnerable group is that, in stark contrast to security surveillance programs, the launch of the A1C registry provoked virtually no response. On July 13, 2005, the Department published in the City Record a notice of its intention to create the A1C registry and to hold a public comment period.<sup>153</sup> On August 16, 2005, the Department held a public hearing on its proposal.<sup>154</sup> In response, the Department received only thirty-one written comments;<sup>155</sup> at the hearing, six health care practitioners and one member of the health care technology industry testified in support, and three private individuals testified in opposition.<sup>156</sup> No civil liberties organization commented on the proposal.<sup>157</sup> Despite its involvement in privacy debates relating to AIDS and bioterrorism surveillance, the ACLU was not even aware of the proposal.<sup>158</sup>

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<sup>151</sup> Gostin, *supra* note 63, at 87.

<sup>152</sup> See Abigail C. Saguy & Kevin W. Riley, *Weighing Both Sides: Morality, Mortality and Framing Contests Over Obesity*, 30 J. HEALTH POL. POL'Y & L. 869, 912–13 (2005) (providing a “detailed analysis of current debates over body weight and health” and concluding that they contain “heated struggles over framing and morality” which “have important implications for social inequality” and include “framing obesity as risky behavior . . . [and] as visible proof of bad food choices and refusal to exercise” and a strong suggestion that obese individuals are to blame for their health status). See generally Lauren Jones, Note, *The Framing of Fat: Narratives of Health and Disability in Fat Discrimination Litigation*, 87 N.Y.U. L. REV. 1996 (2012).

<sup>153</sup> See N.Y.C. Dep't of Health & Mental Hygiene, Notice of Adoption to Amend Article 13 of the New York City Health Code (2005), available at <http://home2.nyc.gov/html/doh/downloads/pdf/public/notice-adoptiona1c.pdf>.

<sup>154</sup> ARTICLE 13 PUBLIC HEARING, *supra* note 63, at 1.

<sup>155</sup> COLGROVE, *supra* note 3, at 248.

<sup>156</sup> ARTICLE 13 PUBLIC HEARING, *supra* note 63, at 11–57.

<sup>157</sup> Fairchild, *supra* note 53, at 175 (“Remarkably, none of the . . . privacy advocates and organizations that had been so engaged in debates about surveillance during the past two decades of heightened concerns spawned by the AIDS epidemic, the federal Privacy Rule, and bioterrorism appeared at the public hearing or made any comment on diabetes surveillance.”).

<sup>158</sup> Fairchild & Alkon, *supra* note 32, at 577 (“The American Civil Liberties Union . . . had been unaware of the proposal and hence missed the opportunity to comment at the public hearing.”).

With a few notable exceptions,<sup>159</sup> the public health community has responded to the A1C registry with approval, and the legal community has not responded much at all. Of the handful of commentators on the program, most emphasize its potential as a public health tool.<sup>160</sup> Perhaps even more surprising, no one has challenged the program in court. In addition, despite similarities between the A1C Registry and an HIV surveillance program proposed by the Department at the same time,<sup>161</sup> the objections of the better-organized HIV community “held more traction . . . [and] effectively thwarted more aggressive surveillance.”<sup>162</sup> The HIV proposal prompted “both the medical community and a wider public [to take] notice and . . . grapple with the meaning of expanded surveillance.”<sup>163</sup>

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<sup>159</sup> See, e.g., Krent et al., *supra* note 67, at 12–37 (cataloging legal and ethical objections to the A1C Registry); Mariner, *supra* note 77, at 149–51 (arguing that the justifications put forth for the A1C Program fail to satisfy basic principles of autonomy and patient privacy); Wendy K. Mariner, *Mission Creep: Public Health Surveillance and Medical Privacy*, 87 B.U. L. REV. 347, 350–60 (2007) [hereinafter Mariner, *Mission Creep*] (surveying a wide range of modern public health surveillance activities, including the A1C registry, and concluding that they lack “defensible principles that define the scope and limits of state power to collect personally identifiable medical information”); Paula M. Trief & Richard A. Ellison, *Mandated Diabetes Registries Will Not Benefit Persons with Diabetes*, 168 ARCHIVES INTERNAL MED. 799, 799 (2008) (“We believe that [mandatory registries like New York’s A1C Program] will be ineffective, will undermine the physician-patient relationship and the expectation of medical privacy, is ethically compromised, and could be dangerous; thus, we take the position against the establishment of such a registry.”); Wilson, *supra* note 45, at 674–77 (arguing that the A1C Registry raises serious privacy concerns and advocating privacy tort law as the best source of protection against impermissible government invasions into medical privacy).

<sup>160</sup> For example, Michelle Mello and Lawrence Gostin argue that “as long as adequate data safeguards are maintained, [the A1C Registry’s] minimal intrusion into patients’ privacy seems more than justified by the potential value of the registry information.” Mello & Gostin, *supra* note 34, at 577. Amy Fairchild argues that the A1C Registry is important “not [because] it raises questions about privacy” but because it represents a possible direction for health care reform. Fairchild, *supra* note 63, at 572–73. Clarissa Barnes et al. argue that the A1C Registry “establish[es] a novel framework for public health monitoring and decision making that has already begun to raise awareness of the diabetes epidemic,” that “[e]pidemics require bold public health action,” and that the A1C Registry is a “worthwhile experiment” that potentially should be replicated nationwide. Clarissa G. Barnes et al., *Mandatory Reporting of Noncommunicable Diseases: The Example of The New York City A1C Registry (NYCAR)*, 9 VIRTUAL MENTOR 827, 829 (2007). Mary Ann Banjeri and Robyn Stewart argue that, although the A1C Registry alone is insufficient to improve diabetes outcomes, it is a valuable public health tool because it permits tracking A1C levels over time, information which could be used to recommend and evaluate interventions. Mary Ann Banjeri & Robyn B. Stewart, *A Public Health Approach to the Diabetes Epidemic: New York City’s Diabetes Registry*, 6 CURRENT DIABETES REP. 169, 170 (2006).

<sup>161</sup> See Goldman et al., *supra* note 51, at 808 (describing similarities in the proposed HIV surveillance initiative and the A1C Registry).

<sup>162</sup> Fairchild & Alkon, *supra* note 32, at 584.

<sup>163</sup> *Id.* at 562.

### C. *Strict Scrutiny Should Apply*

So far, this Note has suggested in part that emergent public health surveillance programs invade an extremely important personal privacy interest. Courts can and should recognize that privacy interest as “fundamental” for purposes of the Fourteenth Amendment. Accordingly, constitutional challenges to emergent public health surveillance should be analyzed under a strict scrutiny standard.<sup>164</sup>

Courts *can* apply a strict scrutiny standard because, contrary to commentators’ widespread assumption, a deferential standard of review need not apply in the context of emergent public health surveillance programs. No court has considered the privacy implications of programs like the A1C Registry,<sup>165</sup> and the few relevant precedents leave room to adjust Fourteenth Amendment analysis as public health surveillance develops (much as courts have adjusted Fourth Amendment analysis in response to developments in security surveillance).<sup>166</sup>

Courts should do so for at least two reasons. First, the personal privacy interest at stake satisfies existing tests for a “fundamental” right. Second, emergent programs are likely to involve ongoing and increasingly comprehensive surveillance and analysis of a wide range of personal behaviors. If the interest at stake in emergent programs is *not* recognized as “fundamental,” it is difficult to imagine that Fourteenth Amendment protection would apply at all to personal privacy outside of the subject matter domains already specifically identified by courts.

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<sup>164</sup> There are several approaches to challenging the legality of emergent forms of public health surveillance. I advocate heightened constitutional scrutiny for two reasons: (i) it would apply to all emergent programs, and (ii) as described in Part III, heightened constitutional scrutiny imposes a tailoring requirement, but does not invalidate useful and appropriate public health surveillance. For additional arguments that the A1C Registry in particular is unlawful, see Mariner, *supra* note 77, at 129–31, 139–44. Mariner identifies two additional reasons the A1C Registry is illegal: (i) the Health Department’s regulatory authority over clinical laboratories under the New York City Charter does not include the power to mandate reporting of individually identifiable information; and (ii) the Department’s use of A1C constitutes “research” which requires patient consent. *Id.*

<sup>165</sup> In a similar vein, Mariner has observed that “[w]hile the Supreme Court has granted considerable deference to legislative determinations of the need for mandatory reporting, it has not considered data uses far removed—both in time and function—from immediate investigations where the information contained names.” Mariner, *Mission Creep*, *supra* note 159, at 381. Mariner further notes that “[p]articularly unsettled . . . are both the characterization of the right to privacy in one’s personal medical information and the standard of review to be applied in evaluating laws compelling disclosure.” *Id.*

<sup>166</sup> See *supra* notes 94–102 and accompanying text (describing medical privacy precedents which suggest that the constitutional analysis of public health surveillance programs would change if the scope of surveillance increased).

The precise method for determining that a right is “fundamental”—and therefore protected under the Due Process Clause of the Fourteenth Amendment—is somewhat obscure.<sup>167</sup> Courts and commentators have suggested that the confusion arises in part because the Supreme Court employs at least two different tests.<sup>168</sup> In *Washington v. Glucksberg*,<sup>169</sup> the Supreme Court emphasized the importance of historical practice and national tradition.<sup>170</sup> Since *Glucksberg*, courts have usually asked whether the purportedly fundamental right is “deeply rooted in this Nation’s history and tradition”<sup>171</sup> to determine whether it is fundamental for the purposes of the Fourteenth Amendment.<sup>172</sup>

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<sup>167</sup> See, e.g., Lee Goldman, *The Constitutional Right to Privacy*, 84 DENV. U. L. REV. 601, 602 (2006) (explaining that because of the “political differences of the Justices” and the “lack of any clear conceptualization” of substantive due process doctrine, “determining whether a fundamental right exists has proven to be a Herculean task”); Kenneth L. Karst, *The Freedom of Intimate Association*, 89 YALE L.J. 624, 625–27, 664 (1980) (describing the Supreme Court’s 1965 decision in *Griswold v. Connecticut*, 381 U.S. 479 (1965), and fifty subsequent cases as the “revival of substantive due process” and as an act of “judicial evasion” about the nature of the doctrine).

<sup>168</sup> See *Abigail Alliance for Better Access to Developmental Drugs v. Von Eschenbach*, 445 F.3d 470, 476 (D.C. Cir. 2006), *rev’d en banc*, 495 F.3d 695 (D.C. Cir. 2007) (noting that the Supreme Court uses “two distinct approaches” in fundamental rights jurisprudence, one which “prob[es] what personal dignity and autonomy demand” and another which “refer[s] to the Nation’s history and legal tradition”) (internal quotation marks and citations omitted); Goldman, *supra* note 167, at 602 (noting that more liberal Justices “ask whether a right is central to personal dignity and autonomy or is at the heart of liberty,” while more conservative Justices “insist that a right is not fundamental unless it is ‘deeply rooted in this Nation’s history and tradition’ and ‘implicit in the concept of ordered liberty,’” and criticizing the first test as “too indeterminate” and the latter as “protecting only those rights that don’t need protection”); Brian Hawkins, Note, *The Glucksberg Renaissance: Substantive Due Process Since Lawrence v. Texas*, 105 MICH. L. REV. 409 (2006) (arguing that the method of identifying fundamental rights employed by the Supreme Court in *Lawrence v. Texas*, 539 U.S. 558 (2003), fundamentally conflicts with the method applied in *Washington v. Glucksberg*, 521 U.S. 702 (1997), and that the *Glucksberg* approach is dominant).

<sup>169</sup> 521 U.S. at 702. In *Glucksberg*, the Supreme Court held that a Washington State ban on assisted suicide did not violate the Due Process Clause of the Fourteenth Amendment, and found that there is no fundamental right to commit suicide or to receive assistance in so doing. *Id.* at 735.

<sup>170</sup> *Id.* at 720–21 (“[W]e have regularly observed that the Due Process Clause specially protects those fundamental rights and liberties which are, objectively, ‘deeply rooted in this Nation’s history and tradition,’ and ‘implicit in the concept of ordered liberty’ . . . .” (quoting *Moore v. City of E. Cleveland*, 431 U.S. 494, 502 (1977) (plurality opinion); *Palko v. Connecticut*, 302 U.S. 319, 325 (1937))).

<sup>171</sup> *Glucksberg*, 521 U.S. at 720–21 (quoting *Moore*, 431 U.S. at 502).

<sup>172</sup> Hawkins, *supra* note 168, at 426 (“The various elements of the *Glucksberg* Doctrine continue to pervade substantive due process decisions . . . . Far and away, the most commonly utilized element of the *Glucksberg* Doctrine is the History and Tradition Inquiry.”).

The first task of a court applying any test is to characterize the purportedly fundamental interest at stake.<sup>173</sup> Emergent public health surveillance programs present an interesting challenge to doing so, because they employ new and evolving technologies. As a result, there is not a readily available concept of the privacy interest actually or potentially invaded, or a consensus about why it is important. What is clear is that the surveillance at issue in emergent public health surveillance verges on comprehensive in both depth and breadth. Given the methods of surveillance and the nature of the health conditions likely to be targeted, emergent programs may involve the lifetime collection of information about the behaviors and habits of millions of people. Such surveillance invades an area of personal privacy that previously challenged programs did not, and it does so on an unprecedented scale.

In addition, there are some jurisprudential indications that a new—and constitutionally significant—privacy interest is at stake. Courts are currently grappling with the implications for Fourth Amendment jurisprudence of both continuous surveillance and sophisticated data analysis capabilities.<sup>174</sup> A number of courts have concluded that continuous government surveillance of public movements has constitutional significance, even though episodic or short-term gathering of the same information does not.<sup>175</sup> However, even while affirming that there is an important difference between the privacy interest invaded by information-gathering that is limited in duration or frequency, and the privacy interest invaded by the continuous gathering of similar information, courts have generally not explained what it is.<sup>176</sup>

Fortunately, a precise definition of the interest invaded by emergent programs is not required: A fundamental right to personal

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<sup>173</sup> The *Glucksberg* test requires a “careful description” of the asserted fundamental right. *Glucksberg*, 521 U.S. at 721.

<sup>174</sup> See *supra* Part II.B (describing changes in Fourth Amendment jurisprudence that respond to new features of security surveillance programs, and arguing that emergent public health surveillance programs share those features).

<sup>175</sup> See *supra* notes 110–13 and accompanying text (noting how continuous surveillance affected the constitutional analysis in recent cases).

<sup>176</sup> See, e.g., *People v. Weaver*, 909 N.E.2d 1195, 1203 (N.Y. 2009) (explaining that continuous surveillance of a criminal suspect’s public movements “realistically could not have been done without GPS” and concluding without explanation that “this dragnet use of the technology . . . to pry into the details of people’s daily lives is not consistent with the values at the core of [the New York Constitution]”). The D.C. Circuit’s invocation of the “mosaic theory” in *United States v. Maynard* provides a uniquely descriptive account of the difference between limited and prolonged surveillance. 615 F.3d 544, 562 (D.C. Cir. 2010) (invoking the mosaic theory); *supra* notes 112–13 and accompanying text (describing mosaic theory and citing *Maynard*).

privacy is deeply rooted in this country's history and tradition. A complete account of legal and cultural protections for personal privacy is far beyond the scope of this paper, but two examples are particularly worth noting. First, the history of Fourth Amendment jurisprudence demonstrates that the "most sacred of all areas . . . is the home," not because "it is a physical structure in which someone chooses to live," but because there is a societal consensus that people have "virtually unlimited expectations of privacy from intrusions" into their homes.<sup>177</sup> A cursory review of Supreme Court cases suggests that we protect the "home" at least in part because it serves as a proxy for personal privacy.<sup>178</sup> Scholars have made the same observation.<sup>179</sup> Moreover, robust Fourth Amendment protection of the home is a product of a deep national commitment to preventing government incursions upon personal privacy that dates to the founding era.<sup>180</sup> Second—and also relevant in the context of emergent public health surveillance programs—there is a clear history of judicial and legislative protections against nonconsensual disclosures of medical information.<sup>181</sup>

Fourth Amendment jurisprudence and commentary on security surveillance programs identify features of modern government surveillance that (i) raise serious concerns about the nature of the privacy invasion, and (ii) in some cases have prompted courts to expand the scope of corresponding constitutional privacy protections. The similar-

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<sup>177</sup> Stephen P. Jones, *Reasonable Expectations of Privacy: Searches, Seizures, and the Concept of Fourth Amendment Standing*, 27 U. MEM. L. REV. 907, 957–58 (1997).

<sup>178</sup> See, e.g., *Kyllo v. United States*, 533 U.S. 27, 37 (2001) (stating that "[i]n the home . . . all details are intimate details"); *United States v. Dunn*, 480 U.S. 294, 301 n.4 (1987) (emphasizing that the "primary focus" in determining what physical spaces constitute the "home" for the purposes of the Fourth Amendment is "whether the area in question harbors those intimate activities associated with domestic life and the privacies of the home"); *Katz v. United States*, 389 U.S. 347, 351 (1967) ("[T]he Fourth Amendment protects people, not places.").

<sup>179</sup> See, e.g., Stern, *supra* note 116, at 926 (explaining that psychological research demonstrates that privacy is important to people not as a right of territorial exclusion, but because it "enables control over self-disclosure and allows others to access the individual's self," whereas "[p]hysical space is important only insofar as it secures the ability to expose or conceal different aspects of our self to others"); *id.* at 919 (summarizing social historians' finding that "industrialization recreated the home as a 'private place'" and giving examples of nineteenth-century protections for personal privacy and reputation).

<sup>180</sup> See James Q. Whitman, *The Two Western Cultures of Privacy: Dignity Versus Liberty*, 113 YALE L.J. 1151, 1211–12 (2004) (stating that "suspicion of the state has always stood at the foundation of American privacy thinking" and tracing the history of the right of privacy from its "starting point" in the "late eighteenth century, and especially . . . the Bill of Rights, with its vigorous circumscription of state power" to its maturation over time to a "much more far-reaching right against state intrusion into our lives").

<sup>181</sup> See Ralph Ruebner & Leslie Ann Reis, *Hippocrates to HIPAA: A Foundation for a Federal Physician-Patient Privilege*, 77 TEMP. L. REV. 505, 508–09 (2004) (describing state and federal legislative and judicial protections for medical privacy).

ities between emergent public health surveillance and security surveillance provide an additional indication that emergent programs may necessitate heightened constitutional privacy protections.

Recognizing that the privacy interest at stake is fundamental would trigger strict scrutiny, under which a reviewing court would inquire whether the challenged surveillance program was narrowly tailored to further a compelling government interest.<sup>182</sup> In one sense, the proposed analysis would not depart from past practice. Arguably, the public health surveillance programs reviewed by courts to date have not involved a fundamental privacy interest, due to technological limits on the breadth and depth of surveillance, the type of information collected, or program design. In particular, most public health surveillance programs, such as those that involve anonymized or consensual data collection, do not intrude upon a fundamental privacy right at all. In addition, the strict scrutiny analysis may be satisfied when the surveillance model at the heart of emergent programs—ongoing, intimate, and individualized surveillance—targets people with a highly infectious disease in order to prevent the disease from spreading. The critical question is whether emergent surveillance programs satisfy the narrow tailoring requirement of a strict scrutiny analysis. Part III describes one approach to finding an answer.

### III

#### ESSENTIAL FEATURES OF A STRICT SCRUTINY ANALYSIS

In Part A, I argue that a court reviewing an emergent public health surveillance program under a strict scrutiny standard should focus its narrow tailoring analysis on the efficacy of the public health

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<sup>182</sup> In *Roe v. Wade*, 410 U.S. 113 (1973), the Supreme Court first applied the strict scrutiny standard (narrowly tailored to a compelling government interest) to a right deemed “fundamental” for purposes of the Fourteenth Amendment Due Process Clause. See Richard H. Fallon, Jr., *Strict Judicial Scrutiny*, 54 UCLA L. REV. 1267, 1283 (2007); see also *Roe*, 410 U.S. at 155–56 (“Where certain fundamental rights are involved, the Court has held that regulation limiting these rights may be justified only by a compelling state interest . . . and that legislative enactments must be narrowly drawn to express only the legitimate state interests at stake.”) (internal quotation marks and citations omitted). Today, when a government program intrudes upon a fundamental interest protected by the Fourteenth Amendment, a narrow tailoring analysis applies. See, e.g., Stephen A. Siegel, *The Origin of the Compelling State Interest Test and Strict Scrutiny*, 48 AM. J. LEGAL HIST. 355, 355 (2006) (“The principle that some governmental actions are permissible only if they promote a ‘compelling state interest,’ and the doctrine of strict scrutiny of which it is an integral part . . . come into play . . . whenever government . . . burdens a fundamental interest.”); see also *Whalen v. Roe*, 429 U.S. 589, 607 (1977) (Brennan, J., concurring) (“[A] statute that did effect [a deprivation of constitutionally protected privacy interests] would only be consistent with the Constitution if it were necessary to promote a compelling state interest.”).

interventions enabled by the challenged surveillance program. Many public health activities would satisfy a stringent efficacy requirement. However, two kinds of interventions should not: those that are effectively indistinguishable from surveillance and, in the case of noncontagious, non-exposure related disease, those that are unlikely to improve the health of the individuals surveilled. In Part B, I analyze the A1C Registry and conclude that it probably does not survive a narrow tailoring analysis because it likely cannot enable more than de minimis health improvements for diabetics. I propose several ways the program can be changed to comport with the proposed Fourteenth Amendment requirements.

### A. *Efficacy of Government Intervention*

Strict scrutiny requires that an emergent public health surveillance program that infringes upon a fundamental right to privacy be narrowly tailored to achieve a compelling government purpose. Emergent public health surveillance programs would likely survive a strict scrutiny analysis in many contexts, like serious infectious disease and exposure investigations.<sup>183</sup> Assuming that governments have a compelling interest in combatting widespread and costly chronic conditions, the critical question is whether a particular emergent public health surveillance program is narrowly tailored to meet that interest. The principal requirement of a narrow tailoring analysis is that the government intrusion “must be necessary in order to be justified.”<sup>184</sup> The Supreme Court articulates the standard as a requirement that “the government’s chosen means be ‘the least restrictive alternative’ that would achieve its goals.”<sup>185</sup> In the context of public health programs, asking whether surveillance is “necessary” should mean—at a minimum—asking whether the surveillance enables the government to improve the public health. Accordingly, to evaluate the constitutional status of emergent public health surveillance programs, courts should consider whether those programs enable public health interventions that are more than minimally effective. Surveillance that targets individuals with non-communicable health conditions but does *not* enable interventions that improve the health of the surveilled indi-

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<sup>183</sup> In many infectious disease and exposure investigations, knowing the identity of all persons affected enables effective government intervention. Recent examples include West Nile Virus, SARS, and pandemic influenza. Once health officials know that individuals have been exposed to the relevant pathogen, they can “treat those who have already been exposed to the pathogen to minimize the health consequences, vaccinate some or all of the population to prevent further infection, and identify and isolate cases to prevent further transmission.” Stoto, *supra* note 9, at 711–12.

<sup>184</sup> Fallon, *supra* note 182, at 1326.

<sup>185</sup> *Id.* (quoting *Ashcroft v. ACLU*, 542 U.S. 656, 666 (2004)).

viduals does not advance the government's public health goals. By the same token, emergent public health surveillance programs are not the "least restrictive alternative" available if equally or more effective public health measures can be implemented without comprehensive, individually-identified data.<sup>186</sup> Under the proposed narrow tailoring analysis, a government would have a compelling interest in fighting the "obesity epidemic" but an emergent public health surveillance model would be appropriate only if it enabled interventions that improved health or mitigated risk for the individuals surveilled.<sup>187</sup>

Historically, there was no need to make explicit an efficacy requirement for public health surveillance programs, because governments can and have effectively combatted the spread of serious communicable disease. Quarantine and other restrictions may be draconian, but at least they work.<sup>188</sup> As government broadened public health surveillance to include *non-infectious* disease, it generally did not engage in extreme invasions of privacy, and it generally conducted anonymous statistical surveillance only.<sup>189</sup> By contrast, emergent public health surveillance, which in many ways replicates the model deployed to combat infectious diseases like tuberculosis, *and* which targets diseases that are not communicable or exposure-related, raises novel constitutional concerns about public health surveillance.

Diabetes is not infectious; neither is obesity, nor are obesity-related chronic conditions. There are no individually-targeted

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<sup>186</sup> See Fallon, *supra* note 182, at 1326 ("A law would not be necessary to achieve its ends if the government could accomplish the same result while inflicting lesser burdens on protected rights."). As an alternative to surveillance of individuals, Michael Stoto argues that "[w]ith respect to diabetes and its risk factors, it may be more effective to identify the population groups that are highly affected and target risk reduction and treatment strategies at them, rather than at individuals." Stoto, *supra* note 9, at 718. Similarly, "[i]dentifying schools with a high proportion of overweight children and enhancing their physical education programs and altering their food availability may be more effective and less stigmatizing in the long run than notifying the parents of children who are overweight." *Id.*

<sup>187</sup> For example, a program that provides nutritious food to low-income pregnant women would further the government's interest in fighting the obesity epidemic because of the demonstrated connection between malnutrition *in utero* and adulthood obesity. See, e.g., Gian-Paolo Ravelli et al., *Obesity in Young Men After Famine Exposure In Utero and Early Infancy*, 295 *NEW ENG. J. MED.* 349 (1976) (reporting the results of a study showing a correlation between malnutrition *in utero* and adulthood obesity). However, no invasive surveillance would be required to operationalize that program, or any other similar government provision of resources.

<sup>188</sup> See *supra* notes 12–19 and accompanying text (describing nineteenth-century tuberculosis surveillance and intervention programs that combatted the spread of tuberculosis, and explaining that quarantine programs were ubiquitous in the colonial era).

<sup>189</sup> See *supra* Part I.A (describing modern public health surveillance).

interventions that can stop a chronic condition from “spreading.”<sup>190</sup> In addition, there is no single action that fixes or dramatically improves the affected individual’s health status. Instead, secondary prevention (preventing a condition for which one is at risk) and tertiary prevention (avoiding complications from a condition) both require lifetime effort by the individuals whose health is at risk.<sup>191</sup> For many chronic conditions, that effort is directed to mundane, but personal, decisions about behavior and lifestyle—what to eat, how much stress to accept in jobs or personal life, how much to exercise, and what proportion of limited time and energy to devote to health management.

Accordingly, with respect to noncommunicable, non-exposure related health conditions, two types of government public health activities should not be considered sufficiently effective to justify the privacy invasion inherent in the emergent public health surveillance model. First, activities that are essentially surveillance—like tracking diseases over time and evaluating the success of public health initiatives—provide no direct benefit to the individuals surveilled. Moreover, traditional models of public health surveillance can support disease tracking and program evaluation.<sup>192</sup> Second, government

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<sup>190</sup> One highly publicized study, however, found that having obese friends increases a person’s risk of becoming obese. See Gina Kolata, *Find Yourself Packing It On? Look Around at Your Friends*, N.Y. TIMES, July 26, 2007, at A1. After evaluating a social network of 12,067 people over a period of thirty-two years and finding that a person’s chance of becoming obese increases if a friend, sibling, or spouse becomes obese, the researchers concluded that “obesity appears to spread through social ties.” Nicholas A. Christakis & James H. Fowler, *The Spread of Obesity in a Large Social Network over 32 Years*, 357 NEW ENG. J. MED. 370, 370 (2007). The health policy implications of the study—and the intuitive proposition that behavior is influenced by the behavior of those with whom one is intimately socially connected—are beyond the scope of this Note. Moreover, they do not alter the basic claim that infectious diseases are fundamentally different from chronic conditions: If extreme privacy invasions to combat the former are justified, it is because infectious disease poses a high and immediate risk to all members of the community and because government intervention effectively prevents the disease from spreading. The same justification does not apply to diabetes, obesity, or other chronic conditions, even if the types of intervention suggested by the “infection” analogy were practicable.

<sup>191</sup> See Steven M. Teutsch & Jeffrey R. Harris, *Introduction to PREVENTION EFFECTIVENESS: A GUIDE TO DECISION ANALYSIS AND ECONOMIC EVALUATION* 7–8 (Anne C. Haddix et al. eds., 2d ed. 2003) (“Primary prevention targets risk factors to prevent occurrence of disease or injury. Secondary prevention targets subclinical disease through early identification and treatment. Tertiary prevention is aimed at an established disease or injury to ameliorate progression and maximize function for the person affected.”).

<sup>192</sup> The contrast between the majority and the dissent in one early public health surveillance case suggests that program improvement and analysis is insufficient to justify intrusive public health surveillance, even under a rational basis standard. In *Schulman v. New York City Health and Hospitals Corp.*, the New York Court of Appeals assessed the constitutionality of a program that required doctors to file, with the City Department of Health, information about patients upon whom they performed an abortion. 342 N.E.2d 501 (N.Y. 1975). The majority upheld the program, emphasizing the fact that New York City had

interventions that target “lifestyle” conditions should be viewed skeptically under an efficacy standard because—as supporters of the emergent public health model frequently argue—“a person’s own behavior is often the root cause of [obesity and obesity-related conditions like diabetes].”<sup>193</sup> It is almost a platitude to say that human habits are hard to change, even when the human involved desperately wants to change them. With respect to diabetes, a comprehensive review of diabetes research and literature published between 1985 and 2001 revealed that “simply improving the person’s level of knowledge rarely, if ever, led to the type [of] behavior changes necessary to manage the disease effectively.”<sup>194</sup> The public health and medical communities have not yet found a way to induce the kinds of behavioral changes needed both to reduce the impact of obesity, diabetes and other chronic conditions, and to rein in escalating health care costs.<sup>195</sup>

### B. Application: Why the A1C Registry Likely Fails Strict Scrutiny

Most commentators assume that a rational basis standard of review would apply to New York City’s A1C Registry,<sup>196</sup> and accordingly predict that the program would survive a constitutional

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recently created a “pilot program [that] pioneered legalized abortion” and had a corresponding responsibility to eliminate the “shoddy and dangerous conditions under which women were forced to submit to abortion before legalization.” *Id.* at 505. Dissenting in *Schulman*, Justice Wachtler found that the program required “too much information” because he found that the only plausible public health objective of the surveillance was “the compilation of public health data to provide an empirical basis for future evolution” in the practice area. *Id.* at 509 (Wachtler, J., dissenting). Judge Wachtler concluded that an identical public health benefit could be achieved *without* individually identifying patients, and dissented on the ground that the state’s “power to promulgate a form seeking vital statistics does not include the power to probe into private matters.” *Id.* (Wachtler, J., dissenting).

<sup>193</sup> See, e.g., Gostin, *supra* note 63, at 87–88 (advocating legal “tool[s]” that should be used to fight obesity, in view of the fact that obesity is “primarily” caused by “[i]ndividuals[.] . . . personal choices about their diet, exercise, and lifestyle,” but also noting that “[a] key question is whether aggressive surveillance . . . offers sufficient benefits” to justify invasion of privacy).

<sup>194</sup> Kathleen Krichbaum et al., *Exploring the Connection Between Self-efficacy and Effective Diabetes Self-management*, 29 DIABETES EDUCATOR 653, 655 (2003).

<sup>195</sup> See, e.g., Atul Gawande, *The Hot Spotters*, THE NEW YORKER, Jan. 24, 2011, at 40 (describing a uniquely successful, unconventional, and resource-intensive intervention of a doctor in a community with exceptionally high chronic disease rates and medical costs, and reporting extensive evidence that intensive medical care and patient education alone are insufficient to combat either problem). “A lot of what [the doctor] had to do, though, went beyond the usual doctor stuff,” and included everything from urging religious patients to rejoin spiritual communities to cooking lessons. *Id.* at 43.

<sup>196</sup> See *supra* Part II.A (describing the commentary).

challenge.<sup>197</sup> However, applying the strict scrutiny analysis outlined in Part A suggests that the A1C Registry may effect an unconstitutional invasion of privacy. New York City government has a compelling interest in preventing both diabetes and diabetes-related complications. The problem is that the A1C's surveillance model does not enable sufficiently effective interventions.<sup>198</sup> The Department has explained why it believes the A1C Registry is valuable,<sup>199</sup> but its explanation is far from satisfactory. The Department's public statements suggest that comprehensive, individualized data *is* the primary value of the A1C Registry, because it currently enables the government to deliver "feedback" and may enable the government to deliver useful services.<sup>200</sup> In addition, the Department believes the existing A1C Registry interventions can improve patient health outcomes.<sup>201</sup> According to the Department, "[p]ersonal identifiers are essential to enable both accurate surveillance" and communication with health care providers about individual patients.<sup>202</sup> The Department also emphasizes the severity of the diabetes "epidemic," which it argues "warrants an urgent public health response."<sup>203</sup>

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<sup>197</sup> See, e.g., Krent et al., *supra* note 67, at 14 ("[I]n light of *Whalen* and *Schulman* it is likely that New York City's A1C Registry would survive a constitutional challenge."); Wilson, *supra* note 45, at 656 (arguing that "[c]onstitutional privacy protection in its current state . . . is ill-equipped to deal with innovative privacy invasions, such as those created by New York City's diabetes program" and advocating privacy tort law as a more robust source of medical privacy protection).

<sup>198</sup> See *infra* notes 206–09 and accompanying text (describing the ineffectiveness of the A1C Registry's patient notifications).

<sup>199</sup> The Department staff who created and implemented the Program wrote an article explaining their reasons for instituting the program and tentatively concluding that "the benefits [of the registry] will outweigh the potential harms." Shadi Chamany et al., *Tracking Diabetes: New York City's A1C Registry*, 87 MILBANK Q. 547, 548 (2009). In addition, multiple Department documents describing the program and its intended benefits are available on the Department's website. See, e.g., *Diabetes Prevention and Control*, N.Y.C. DEP'T OF HEALTH & MENTAL HYGIENE, <http://www.nyc.gov/html/doh/html/diabetes/diabetes-nycar.shtml> (last visited Sept. 10, 2012).

<sup>200</sup> See, e.g., Press Release, N.Y.C. Dep't Health & Mental Hygiene, *New Diabetes Report Documents Devastating Effects in New York City: Diabetes Hospital Costs Have Doubled in New York City Since 1990* (July 24, 2007), *available at* <http://www.nyc.gov/html/doh/html/pr2007/pr060-07.shtml> ("This registry—the first of its kind in the nation—will enable the Health Department to give clinicians and patients feedback and resources that can improve the quality of care and quality of life for New Yorkers with diabetes."). *But see infra* note 209 and accompanying text (arguing that the A1C Registry does not address unmet medical needs and does not provide resources to diabetics).

<sup>201</sup> See Chamany et al., *supra* note 199, at 551–52 (listing the Department's goals as "(1) to raise providers' awareness regarding the level of glycemic control in their patient panels; (2) to enable providers to take action for those at highest risk; and (3) to inform and guide patients who are at risk for complications").

<sup>202</sup> *Id.* at 555.

<sup>203</sup> *Id.* at 548, 559.

The A1C Registry interventions likely do have some value. The patient letters<sup>204</sup> inform by telling people that their blood sugar is poorly managed, by explaining that high blood sugars have adverse health consequences, and by advising diabetics to get regular medical care.<sup>205</sup> However, there are at least two reasons why informing patients in this manner should not be considered sufficiently effective to justify the surveillance component of the A1C Registry. First, the City government is not the best entity to inform diabetics of their health status and its associated risks. One alternative is community health providers, which have the significant advantages of (i) interacting with patients under normal conditions of confidentiality and (ideally) trust, and (ii) being far better situated to connect patients with resources that may help in each individual case.<sup>206</sup> More fundamentally, the ravages of uncontrolled diabetes are common knowledge in the communities most heavily impacted by the disease, even if the quantified risk level associated with each A1C test result is not.<sup>207</sup> Second, the benefit of an unsolicited letter stating that the recipient is unhealthy seems dubious at best. After all, far more resource-intensive programs intended to help *willing* diabetic participants make

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<sup>204</sup> See N.Y.C. DEP'T OF HEALTH & MENTAL HYGIENE, NEW YORK CITY A1C REGISTRY: IMPROVING DIABETES CARE IN NEW YORK CITY, *supra* note 37, at 22 (providing sample letter).

<sup>205</sup> Recent Community Health Surveys conducted by the Department reveal that a significant number of diabetics in New York City do not know their A1C levels. See, e.g., N.Y.C. DEP'T OF HEALTH & MENTAL HYGIENE, DIABETES IN NEW YORK CITY: PUBLIC HEALTH BURDEN AND DISPARITIES, *supra* note 38, at 5-2 ("Four in 5 adults with diabetes in New York City report having had at least 1 hemoglobin A1C test in the past year, but only 16% of those reporting a test know their A1C level."); LYNN D. SILVER & DIANA K. BERGER, N.Y.C. DEP'T OF HEALTH & MENTAL HYGIENE, IMPROVING DIABETES CARE FOR ALL NEW YORKERS 17 (2005), available at <http://www.nyc.gov/html/doh/downloads/pdf/diabetes/diabetes-presentation-a1c-registry.pdf> (citing a 2002 Department survey which found that, in New York City, "only 10% of people with diabetes know their A1C"). However, it is unlikely that many diabetics do not know when their diabetes is uncontrolled, because the symptoms of elevated blood sugars are obvious and uncomfortable. Similarly, it is unlikely that diabetics in New York City do not know that uncontrolled diabetes produces severe health consequences: Most diabetics see or experience the ravages of diabetes-related complications on a regular basis. See N.R. Kleinfeld, *Diabetes and Its Awful Toll Quietly Emerge as a Crisis*, N.Y. TIMES, Jan. 9, 2006, at A1 (describing interviews with multiple members of New York City communities with the highest diabetes rates, and reporting that interviewees live with, witness, and fear extremely debilitating complications); N.R. Kleinfeld, *Living at an Epicenter of Diabetes, Defiance and Despair*, N.Y. TIMES, Jan. 10, 2006, at A1 (same).

<sup>206</sup> Some commentators have proposed or noted the existence of alternatives to the A1C Registry that would provide more value to diabetics. See, e.g., Goldman et al., *supra* note 51, at 809-10 (noting that a "far better model for improving the care of diabetes" is already operative in the several public hospitals in New York City; in that model, teams of diabetes health care providers coordinate to track and assist patients).

<sup>207</sup> See *supra* note 205.

needed lifestyle changes have achieved very modest and short-lived success.<sup>208</sup>

The letters to health care providers identifying at-risk patients are arguably more valuable. But again, how valuable? Improving the health outcomes of a diabetic requires at least the following additional steps: (i) the doctor contacts the patient, (ii) the patient visits the doctor, and (iii) the patient implements the doctor's recommendations. The diabetics who testified at the Department's 2005 hearing strongly contested the utility of provider letters.<sup>209</sup> Increasingly, health care providers also recognize that the principal obstacles to successful diabetes management are practical, not informational. Accordingly, some experts have called for a new approach to treating diabetes, which emphasizes identifying and resolving the practical barriers that prevent each individual diabetic from making needed behavioral changes.<sup>210</sup>

Easy modifications to the surveillance component of the A1C Registry surveillance would remove doubt about its constitutional status. For example, the program could be consent based, like Vermont's diabetes registry.<sup>211</sup> Consent would remove privacy concerns; in addition, people who opt in to the program are presumably indicating that they would benefit from reminders about their health status. Alternatively (or additionally), the A1C Registry could identify patients by community or health center, instead of by name and

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<sup>208</sup> See, e.g., Richard Kahn, *Reducing the Impact of Diabetes: Is Prevention Feasible Today, Or Should We Aim for Better Treatment?*, 31 HEALTH AFFAIRS 76, 76–77 (2012) (summarizing results from the national Diabetes Prevention Trial, a Finnish diabetes prevention study and other studies, all of which showed “modest” differences in the degree of weight loss and changes in physical activity levels between the intervention groups and the control groups, and stating that the health status improvements of resource-intensive “complex lifestyle interventions” almost entirely disappear by the patient's fourth year in the program).

<sup>209</sup> For example, Steven Lazarus testified: “I do not believe that diabetes can be managed by anyone other than the patient along with his or her health care team.” ARTICLE 13 PUBLIC HEARING, *supra* note 63, at 45–46. Lazarus added: “The City can collect all the data it wants, but if the patient isn't willing and the doc isn't competent, then it's a waste of time and money. . . . Basically you're collecting sensitive information and spitting it back out to the physician.” *Id.*

<sup>210</sup> Following a systematic review of diabetes literature, a group of health care providers with extensive clinical experience recommended that “[e]ducation sessions need to include less lecture and more practical and interactive exercises where there is skill development in meal planning, problem solving, handling social situations, and dealing with emotional/psychological barriers and issues that will lead to behavior change.” Krichbaum et al., *supra* note 194, at 660. For example, “a person who is able to learn all about diabetes and its effects on the body but who faints at the sight of blood will need help dealing with this fear before learning how to monitor his or her blood glucose level.” *Id.*

<sup>211</sup> See *supra* note 27 (describing the Vermont opt-in system).

personal information. That method would enable city government to direct resources to the communities that need them most.

Advocates of the A1C Registry describe diabetes in New York City as a public health crisis, a financial crisis, and “a raging epidemic.”<sup>212</sup> The rhetoric used by public health officials legitimately concerned about the physical and financial tolls of chronic disease has been useful in bringing public attention to the destructive power of conditions that often seem mundane and undramatic.<sup>213</sup> But the rhetoric is also profoundly misleading.<sup>214</sup> Those who use the word “epidemic” argue that diabetes is so like an infectious disease that it should be treated as one.<sup>215</sup> But diabetes is like an infectious disease only in the sense that it is widespread and increasingly prevalent. Unlike infectious disease, it cannot be “stopped” by government intervention in the lives of people who have it.<sup>216</sup> Proponents also cite the cost of chronic disease and related complications as a justification

<sup>212</sup> ARTICLE 13 PUBLIC HEARING, *supra* note 63, at 20–21. Dr. Eran Bellin testified at the 2005 Department Hearing: “[D]iabetes is a raging epidemic leaving death and disability in its wake. . . . Why do we as a city tolerate the fractionalization of clinical information so that no one responsible for population health in the middle of a diabetes epidemic is capable of identifying who is not getting better?” *Id.* at 20–21, 26.

<sup>213</sup> See, e.g., Kleinfeld, *Diabetes and Its Awful Toll Quietly Emerge as a Crisis*, *supra* note 205 (describing the widespread and severe physical consequences of diabetes on New York City residents); Kleinfeld, *Living at an Epicenter of Diabetes, Defiance and Despair*, *supra* note 205 (same).

<sup>214</sup> See, e.g., Goldman et al., *supra* note 51, at 808 (arguing that “the more general use of the term [epidemic] raises the specter of an acute, contagious disease that spreads rapidly through a population” and that although such labels “may be a useful strategy for raising public awareness . . . the language of epidemic also implicitly justifies an expansion of public health authority”); Saguy & Riley, *supra* note 152, at 913 (“[T]he epidemic framing of obesity conflates the literal and metaphorical meaning of *epidemic*. In the latter, the *epidemic of obesity* represents concern about the spread of immoral behavior.”).

<sup>215</sup> In 2007, a letter written by then-Commissioner Frieden introducing a Department report on diabetes in New York City proclaimed that “[t]his epidemic requires an effective public health response similar to that traditionally associated with communicable diseases.” N.Y.C. DEP’T OF HEALTH & MENTAL HYGIENE, *DIABETES IN NEW YORK CITY: PUBLIC HEALTH BURDEN AND DISPARITIES*, *supra* note 38. Similarly, the Department’s website states: “The epidemic requires the same kind of urgent public health response traditionally accorded to infectious disease outbreaks.” N.Y.C. DEP’T OF HEALTH & MENTAL HYGIENE, *A1C REGISTRY: FREQUENTLY ASKED QUESTIONS*, *supra* note 137, at 1.

<sup>216</sup> The early twenty-first century New York City Health Department “return[ed] to its nineteenth-century roots” by using what New York City Mayor Michael R. Bloomberg described as the “forceful application of the law” as the principal instrument of public health policy. COLGROVE, *supra* note 3, at 255. One commentator believes that then-Commissioner Frieden and Mayor Bloomberg share a belief that “public health is, at least sometimes, an autocratic or paternalistic exercise.” *Id.* Commissioner Frieden consciously modeled his approach on that of Dr. Hermann Biggs, who led the aggressive effort to combat tuberculosis in New York City at the turn of the twentieth century. *Id.*

for emergent public health surveillance.<sup>217</sup> That argument implies, without explaining, that financial crisis—as opposed to a direct threat to the public health—justifies intimate medical privacy intrusions. Coupling the rhetoric of “crisis” with a call for government action suggests that government action can effectively address the crisis. My limited claim here is that the A1C Registry’s model of ongoing, comprehensive, and individualized surveillance may not enable government interventions that sufficiently mitigate risk to the City’s diabetics.

## CONCLUSION

Emergent public health surveillance programs adopt a surveillance model that was developed in the context of infectious disease and apply it to non-communicable health conditions. But the original justification for the extreme privacy invasions at the heart of individualized surveillance no longer applies. In addition, the emergent public health surveillance model shares three features with security surveillance, all of which have been identified as sources of troubling privacy invasions, and at least one of which is changing Fourth Amendment analysis. Courts should recognize that diabetes, obesity, and other chronic conditions that threaten the public health implicate highly personal information, including sensitive medical data and a wide array of personal behaviors. As a result, ongoing, name-based surveillance of populations with those conditions effects an extremely intimate privacy invasion. Applying strict scrutiny to emergent public health surveillance programs would permit those invasions only to the extent necessary to successfully mitigate the risk from diabetes and other chronic diseases.

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<sup>217</sup> In 2005, Commissioner Frieden explained that it was the “business” of the government to know whose diabetes was uncontrolled because diabetes cost New York City an estimated \$5 billion per year. See Associated Press, *Big Brother Wants To Be Diet Cop*, WIRED.COM (July 25, 2005), <http://www.wired.com/medtech/health/news/2005/07/68301?currentPage=all> (“‘What business of the government is it to know that my diabetes is not in control?’ said [Commissioner Frieden]. The answer, he said, is that diabetes costs an estimated \$5 billion a year in treat [sic] in New York . . .”).