

Chapter 2

The Importance of Geography in Disease Surveillance

Abstract The current attention on health care reform in the United States provides an excellent opportunity for professional medical geographers to be engaged in research on population and community health. As the history of disease surveillance in the United States indicates, there is a need for more synthetic and integrative research on disease surveillance systems that can improve health outcomes and quality of care. Such a system would incorporate the principles of an accessible and distributed surveillance infrastructure and multiple streams of data based on shared references to the common geographic locations. Medical geographers are well poised to address the technical demands of these issues, through their knowledge of issues such as spatial data quality and resolution, the legal and ethical complexities of volunteered geographic health information, and the proliferation of web technologies (like Web 2.0 and 3.0). The research methods needed to address these topics span a number of paradigms, from the technical dimensions of GIScience to the social critiques of contemporary human geography – and have the power to engage a broad cross-section of professional geographers.

Keywords Infectious disease • Disease registries • Population health • Public health disease surveillance • Spatial data resolution • Volunteered geographic information

2.1 Introduction

One of the compelling forces behind this book is the current attention on health care reform in the United States. The health information exchanges (HIEs) created by PPACA are designed to improve the delivery of health care services by expediting the delivery of health information and increasing health care access [1–4]. Disease surveillance is an application of the HIEs that is designed to prevent, monitor, and respond to disease outbreaks.

At the most basic level, disease surveillance can be divided into three parts: detecting, understanding, and responding to the spread of disease [5]. A sophisticated disease surveillance system manages “health-related data and information for early warning of threats and hazards, early detection of events, and rapid

Table 2.1 Opportunities and challenges for professional geographers in disease surveillance

Disease diffusion in areas that are not well characterized
Transport of disease vectors between certain population centers
Surveillance capacity building in resource-limited countries
Forecasting future health hazards
Geospatial data infrastructures in health information exchanges
Volunteered geographic information in public health applications
Data sharing, privacy, and ethical issues
Representation of “minority” patients and their “hidden” medical conditions
Synthetic and distributed disease surveillance systems
Geospatial data integration from multiple sources

characterization of the event so that effective actions can be taken to mitigate adverse health effects” [6].

Despite the large body of published research in medical geography and spatial epidemiology [7–10], and public health biosurveillance [11–13], there is relatively little published research addressing the design and implementation of a pro-active, spatio-temporal, disease surveillance system that incorporates the health and environmental factors necessary for a rapid response to and recovery of a disease outbreak. This is because of the difficulties in designing a system that successfully integrates and coordinates many moving parts across multiple scales and many different governance bodies.

The goal of this chapter is to demonstrate that the skills and experiences of professional geographers are essential to the field of disease surveillance. To accomplish this, it will briefly describe the history of disease surveillance in the United States. Then, it will present a survey of geospatial applications in disease surveillance, and highlight the current opportunities and challenges in this field for the professional geographers (Table 2.1).

2.2 A Brief History of Public Health Disease Surveillance in the United States

The earliest records of disease surveillance in the United States are from the colonial era, or eighteenth century, when reports of disease and infections were made to local officials by family members, lodging proprietors, and ship owners and operators. These citizens reported acute infectious disease – like cholera, yellow fever, and smallpox – so that their communities would know about possible epidemics and undertake the necessary control measures [14].

As the use of vital statistics and registries of birth, death and marriage became more prominent, disease reporting became an important way to prevent certain infectious diseases. In the late nineteenth century, Henry Bowditch and members of

the state board of health in Massachusetts asked physicians to report on all infectious diseases detected, on a weekly basis [15]. As the discoveries of Louis Pasteur and Robert Koch enhanced the public's understanding of the role that bacteriology played in disease, it provided a greater role for laboratory diagnostics in disease reporting. Consequently, disease reporting shifted from the domain of sanitarians and social reformers to physicians and diagnostics laboratories. Henceforth, the bacteriological revolution played a vital role in the creation of public health departments and the importance of disease surveillance [16].

To many, disease surveillance offered the hope of vital health care services, lifesaving knowledge, and protection for the individual and community, in the face of epidemics. To others, disease surveillance was regarded as an intrusion of personal privacy and the doctor-patient confidentiality. As public health disease surveillance began to unfold in the late nineteenth century (with the surveillance of tuberculosis and venereal diseases), the American Medical Association (AMA) code of ethics evolved to consider community health prevention, as well as patient privacy rights. In 1903, the AMA code of ethics explicitly permitted exceptions to the doctor-patient confidentiality, especially when "imperatively required by the laws of the state" [17]. In 1912, the AMA code of ethics specifically stated that "A physician may not reveal the confidentiality entrusted to him... unless he is required to do so by law or unless it becomes necessary in order to protect the welfare of the individual or the community" [18].

The debates concerning public health disease surveillance took place against a backdrop of wartime and postwar repression. World War I inspired and reinvigorated discussions on civil liberties and personal freedoms. The Civil Liberties Bureau was created in 1917, and was renamed the American Civil Liberties Union in 1920 [19]. In 1959, the United States Supreme Court upheld the right of the Maryland health department to arrest and fine a homeowner who refused a search for rat infestation because the health inspector did not have a warrant [20].

Furthermore, Cold War concerns provided the catalyst to expand disease surveillance efforts at the federal level. In 1951, the threats of bioterrorism during the Korean War prompted Alexander Langmuir to establish the Epidemic Intelligence Service (EIS) at the Communicable Disease Center (later renamed to be the Centers for Disease Control and Prevention, or CDC) [21]. The EIS facilitated greater interactions between federal and state health departments, and allowed the CDC to play a more prominent role in the coordination and funding of state public health surveillance.

In 1977, the United States Supreme Court ruled in its first public health surveillance case and stated that disease reporting is "an essential part of modern medical practice," citing venereal disease, child abuse, and fetal death reports as legitimate examples of public health reporting [22]. However, with the identification of Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS) in the 1980s, the tensions between patients' privacy and public health reporting began to re-escalate. It wasn't until 1994, when the anti-retroviral agent AZT was shown to reduce HIV transmission between parent and

child that the public sentiment against HIV case surveillance began to wane [23]. In September 1997, the CDC formally called upon all states to adopt a system of HIV case reporting; the move was backed by the AMA and the editorial staff of the New England Journal of Medicine [24, 25]. To allay concerns from the ACLU and patients advocacy groups, the 1999 CDC guidelines stated that any receipt of federal funds for HIV/AIDS surveillance would be contingent upon a demonstration of acceptable security standards to protect patients' identities (e.g., by using uniquely coded identifiers) [26].

Concurrently, in the 1990s, the CDC created the National Environmental Public Health Tracking Program, aimed at building a nationwide network for studying human exposures to environmental hazards (Fig. 2.1). In 2002, Congress allocated funds to help create a system that linked hazard exposure and disease data, and by 2004, the CDC announced funding for 21 local health departments and public health schools to help move toward a national environmental public health tracking system [27]. These attempts to integrate the surveillance of environmental hazards mirrored the progress evident in establishing immunization and birth defects registries. In 1999, the Department of Health and Human Services (DHHS) began funding a program to foster linkages between newborn screenings for genetic defects and other maternal and child health services. By 2003, 12 states and large metropolitan



Fig. 2.1 CDC's National Environmental Public Health Tracking Network website (<http://ephrtracking.cdc.gov/showHome.action>)

areas were establishing integrated child health data systems. Most were focused on linking data on four procedures: vital registration, newborn dried blood spot screening, immunization, and early hearing detection and intervention [28, 29]. Among the most advanced of these systems was Rhode Island's KidsNet, which combined data from nine public health programs to create a child health profile [30].

Looking back on the twentieth century, financial support for the myriad of laws and regulations mandating reporting for a wide range of illnesses had been lacking. Despite the fact that states bore the legal responsibility for determining which diseases should be reportable, they contributed only about a quarter of the resources for surveillance activities [31]. The impact of funding on the completeness rates of reporting of infectious diseases was also evident. The average rate for the high-profile and well-funded surveillance systems covering AIDS, tuberculosis, and sexually transmitted diseases was significantly better than for all other diseases (79 % versus less than 50 %) [32]. Therefore, the financial investments in chronic disease prevention and disease surveillance specified in the Patient Protection and Affordable Care Act (PPACA) of 2010 represent an opportune moment for professional geographers to contribute to the scientific understanding and response to disease outbreaks.

2.3 Geospatial Applications in Disease Surveillance: Current Opportunities and Challenges

After September 11, 2001, the nation's inadequate surveillance capabilities to counter the threat of bioterrorism became apparent. In a study conducted in early 2002, the General Accounting Office concluded that "existing surveillance systems have weaknesses, such as chronic underreporting and outdated laboratory facilities, which raise concerns about the ability of the state and local agencies to detect emerging disease or a bioterrorism threat" [33]. In October 2002, the CDC announced plans for a national syndromic surveillance system as part of the nation's defense against terrorism. Several cities, like New York City and Pittsburgh, also began to develop Early Aberration Reporting Systems (EARS) which were designed to monitor unusual clusters of illness that might suggest a bioterrorist attack [34].

As stated earlier, disease surveillance can be divided into three major components: detecting, understanding, and responding to the spread of disease. Syndromic surveillance systems are designed to detect a disease before an actual diagnosis is made, by using ancillary data sources to predict a clinical outbreak. They act like smoke detectors, sounding alarms before a disease sweeps through a community. The data sources present information from different points along the continuum of the disease process, and allow public health officials to provide health care facilities and professionals with advanced notice of a disease outbreak. Examples of these data sources include sales records of prescriptions and other disease-related consumer products (such as Kleenex tissues, Tropicana orange juice and over-the-counter

medicines), work and school absenteeism records, and increased visits and calls to health care facilities and providers [35].

The second aspect of disease surveillance is understanding the spread of disease. Given the proliferation of geographic information systems (GIS) technology and advanced visualization algorithms, medical geographers have contributed much to this field [8–10, 36]. In addition, geospatial scientists have grappled with issues such as the appropriate data resolution, spatial epidemiological modeling, and developing forecasting models [5, 37–44]. As the spread of disease varies across different geographical landscapes, it is often difficult to understand the spatio-temporal diffusion of disease in areas that are not well characterized geographically. Not surprisingly, sentinel clinics have long been used to monitor certain diseases in resource-limited areas [45, 46]. The patterns of travelers and their visits to sentinel clinics can provide insights into regional illness patterns [47–51]. However, there is much uncertainty surrounding the transport of disease vectors between certain population centers [52–55].

The prevention of future disease outbreaks is the third aspect of disease surveillance. Due to challenges in information technology, infrastructure, public health resources, and the costs of proprietary software, resource-limited countries are not as able to respond to disease outbreaks as developed countries. To address these needs, the Suite for Automated Global Electronic bioSurveillance (SAGES) was developed (Fig. 2.2). SAGES is a collection of modular, flexible, freely-available software tools for electronic disease surveillance. One or more SAGES modules may be used in concert with existing surveillance applications or the entire SAGES suite may be used en masse for an end-to-end biosurveillance capability [56].

Other systems – such as BioSense [57], Distribute [58], EARS [59], and Real-time Outbreak and Disease Surveillance (RODS) [60] – collect, analyze, and display surveillance data so that different health regions and jurisdictions can compare the progression of infectious disease outbreaks. A critical element of disease surveillance systems is the ability to prevent further outbreaks by forecasting the occurrence of a health hazard. BioSINE accomplishes this by providing geospatial and temporal visualization capabilities to traditional surveillance systems. BioSINE is a project funded by the Army’s Telemedicine and Advanced Technology Research Center (TATRC) to rapidly explore, analyze and share trends in public health data. Researchers can use this system to form hypothesis based on the patterns discovered to initiate additional studies that predict future outbreaks [61].

As stated at the beginning of this chapter, the goals around the national HIEs are to expedite the delivery of health information and increase health care access. In the United States, approximately 25 % of people with HIV infection don’t know their HIV status. Moreover, of those who are aware that they’re infected, 50 % are not receiving regular HIV care [62].

In March 2011 the CDC convened a “Consultation on Monitoring the Use of Laboratory Data Reported to HIV Surveillance” meeting to develop recommendations for the legitimate uses of confidential surveillance data in improving patient outcomes. In order to open up the surveillance registries – potentially giving infected

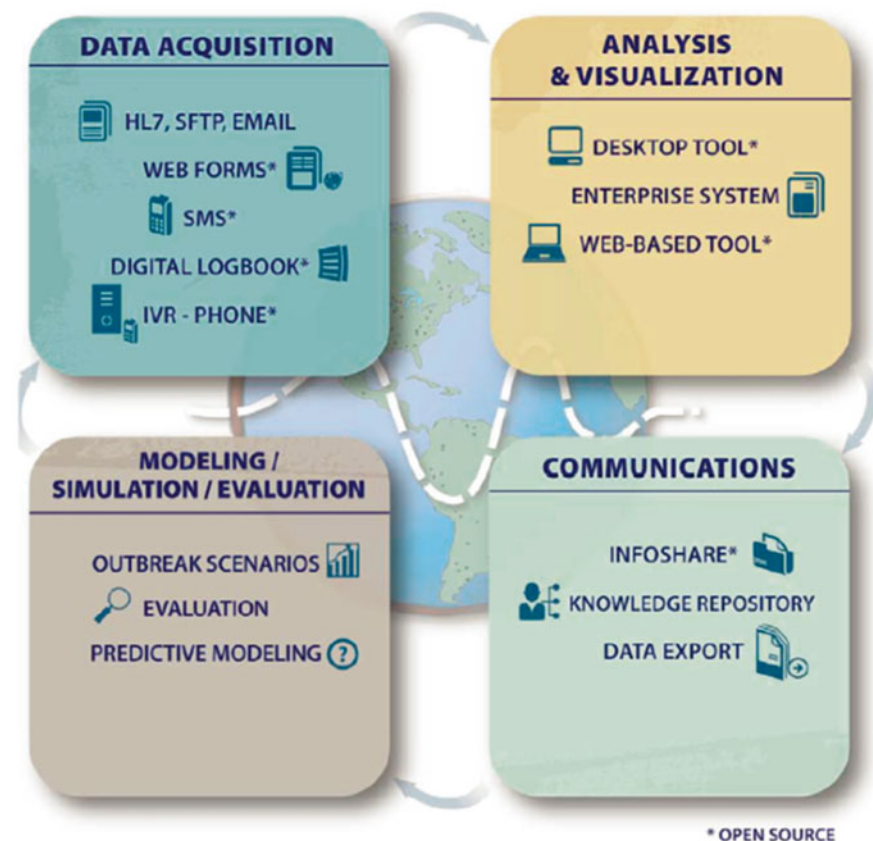


Fig. 2.2 Suite for Automated Global Electronic bioSurveillance (SAGES) – a collection of modular, flexible, and freely available software tools for electronic disease surveillance in resource-limited settings. One or more tools may be used in concert with existing surveillance applications or be used en masse for an end-to-end biosurveillance capability (From Figure 1 in: Lewis et al. [58])

people and clinicians more treatment options – the “Jericho-like” walls used to protect patient confidential must be dismantled [63].

Recognizing the controversies involved in disclosing information from surveillance registries, the state of Louisiana consulted with members of the community, health care providers, and federal health officials on these related ethical matters. As a result, the state Office of Public Health (OPH) created and implemented the Louisiana Public Health Information Exchange (LaPHIE), which allows an “authorized medical provider” to open a patient’s electronic medical record in the state hospital system. The LaPHIE determines whether the patient is an HIV-exposed infant or someone who tested positive for HIV but was either not informed of the results or hasn’t received a CD4 test within the past 12 months. In these instances, the system returns a “point-of-care message,” alerting the caregiver that

the patient is HIV-positive and not receiving care and providing an opportunity to offer appropriate services. At the March 2011 CDC consultation, Dr. Jane Herwehe of Louisiana State University presented data showing that this simple message, which merely initiates a conversation with the patient, has resulted in approximately 75 % of HIV-positive people returning to care during the pilot phase [64].

In order for these success stories to occur in other critical areas, the HIEs initiative must allow for the storage of pertinent geographic information, such as the patient's residential history. In 2011, the Association of American Geographers (AAG) co-sponsored, along with the National Institutes of Health (NIH), a workshop on geospatial infrastructure for medical research to "evaluate the potential development of an NIH-wide geography and geographic information infrastructure ("geospatial infrastructure") to support basic biomedical research and public health applications" [65]. These and other efforts demonstrate that the expertise and tools of professional geographers are essential in the development of disease surveillance systems, primarily in our understanding of disease detection and diffusion processes. Medical geographers are currently investigating how volunteered geographic information can potentially contribute valuable geo-tagged public health information that is useful to disease surveillance efforts [11, 66, 67]. For instance, aggregated search query data – from Google Flu Trends – has been used to estimate influenza activity in near-real time [68]. Given that this information contains a geographic component, several data quality and sharing issues need to be addressed – such as the nature of privacy and ethics in the use of this volunteered mode of disease surveillance.

The ways in which patients and their medical conditions are represented, compiled and examined – from office visits and prescriptions records to daily personal blogs and newspaper stories – have also changed the landscape in which disease surveillance systems operate. While volunteered geographic information will more likely contain the contextual milieu in which a medical condition is noted, the question of whether minority populations or "hidden" conditions are ignored remains unresolved.

In addition, the proliferation of web technologies, such as Web 2.0/Web 3.0 and mashups, holds promising frontiers for medical geographers to develop a new research agenda for disease surveillance that incorporates the principles of an accessible and distributed surveillance infrastructure, integrating multiple sources of data based on shared references to the common geographic locations.

In conclusion, this chapter has demonstrated a need for further integrative research on disease surveillance by the community of professional medical geographers. Topics such as spatial data quality and resolution, the legal and ethical issues of volunteered geographical health information, and the technical demands of formulating a synthetic and integrative disease surveillance system represent the types of research that only geographers can undertake. The research methods needed to address them span a number of paradigms, from the technical dimensions of GIScience to the social critiques of contemporary human geography. Consequently, these questions have the power to engage a broad cross-section of professional geographers.

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