WILEY

Disease Surveillance

A Public Health Informatics Approach

Edited by
JOSEPH S. LOMBARDO
DAVID L. BUCKERIDGE

Contents

Part I: System Design and Implementation

Chapter 2: Understanding the Data: Health Indicators in Disease Surveillance

Part II: Case Studies

Chapter 6: Modern Disease Surveillance Systems in Public Health Practice

Chapter 7: Canadian Applications of Modern Surveillance Informatics

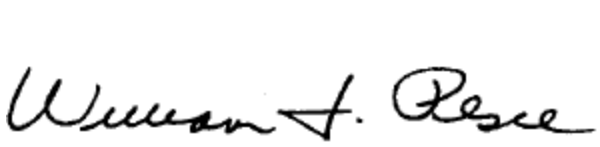
DISEASE SURVEILLANCE

THE WILEY BICENTENNIAL–KNOWLEDGE FOR GENERATIONS

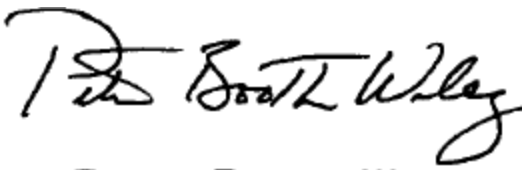
Each generation has its unique needs and aspirations. When Charles Wiley first opened his small printing shop in lower Manhattan in 1807, it was a generation of boundless potential searching for an identity. And we were there, helping to define a new American literary tradition. Over half a century later, in the midst of the Second Industrial Revolution, it was a generation focused on building the future. Once again, we were there, supplying the critical scientific, technical, and engineering knowledge that helped frame the world. Throughout the 20th Century, and into the new millennium, nations began to reach out beyond their own borders and a new international community was born. Wiley was there, expanding its operations around the world to enable a global exchange of ideas, opinions, and know-how.

For 200 years, Wiley has been an integral part of each generation's journey, enabling the flow of information and understanding necessary to meet their needs and fulfill their aspirations. Today, bold new technologies are changing the way we live and learn. Wiley will be there, providing you the must-have knowledge you need to imagine new worlds, new possibilities, and new opportunities.

Generations come and go, but you can always count on Wiley to provide you the knowledge you need, when and where you need it!



WILLIAM J. PESCE
PRESIDENT AND CHIEF EXECUTIVE OFFICER



PETER BOOTH WILEY
CHAIRMAN OF THE BOARD

DISEASE SURVEILLANCE

A Public Health Informatics Approach

Edited by

Joseph S. Lombardo

The Johns Hopkins University
Applied Physics Laboratory
Laurel, Maryland

David L. Buckeridge

McGill University
Montreal, Quebec
Canada

WILEY-
INTERSCIENCE

A JOHN WILEY & SONS, INC., PUBLICATION

Published by John Wiley & Sons, Inc., Hoboken, New Jersey.
Published simultaneously in Canada.

Department within the United States at (800) 762-2974, outside the United States at (317) 572-3993 or fax (317) 572-4002.

Wiley also publishes its books in a variety of electronic formats. Some content that appears in print may not be available in electronic format. For information about Wiley products, visit our web site at www.wiley.com.

Wiley Bicentennial Logo: Richard J. Pacifico

***Library of Congress Cataloging-in-Publication Data*:**

Disease surveillance : a public health informatics approach / [edited by] Joseph S.
Lombardo, David Buckeridge.
p.; cm.
Includes bibliographical references and index.
ISBN 978-0-470-06812-0 (cloth : alk. paper)
1. Public health surveillance. 2. Medical informatics. I. Lombardo, Joseph S., 1946– II. Buckeridge, David, 1970–
[DNLM: 1. Population Surveillance—methods. 2. Public Health Informatics. WA 105
D6117 2007]
RA652.2.P82D57 2007
362.1—dc 22
2006053118

To those public health workers who get the call at 5 P.M.
on Friday afternoon and give freely of their own time
to protect the health of the populations they serve.
It is hoped that the advance disease surveillance methods
described in this book will help them to use their time
and talents more efficiently to accomplish their mission.

Contributors

JEFF ARAMINI, DVM, PHD, Public Health Agency of Canada, Guelph, Ontario, Canada

RAJ ASHAR, MA, The Johns Hopkins University Applied Physics Laboratory (JHU/APL), Laurel, Maryland, USA

STEVEN BABIN, MD, PHD, The Johns Hopkins University Applied Physics Laboratory (JHU/APL), Laurel, Maryland, USA

DAVID BLAZES, MD, MPH, U.S. Naval Medical Research Center Detachment, Lima, Peru

DAVID L. BUCKERIDGE, MD, PHD, McGill University, Montreal, Quebec, Canada

HOWARD BURKOM, PHD, The Johns Hopkins University Applied Physics Laboratory (JHU/APL), Laurel, Maryland, USA

JEAN-PAUL CHRETIEN, MD, PHD, Walter Reed Army Institute of Research, Silver Spring, Maryland, USA

JACQUELINE COBERLY, PHD, The Johns Hopkins University Applied Physics Laboratory (JHU/APL), Laurel, Maryland, USA

DUNCAN COOPER, BSC, MRES, Health Protection Agency, West Midlands, United Kingdom

R. LOREN ERICKSON, MD, DRPH, Walter Reed Army Institute of Research, Silver Spring, Maryland, USA

JONATHAN GLASS, MD, U.S. Naval Medical Research Center Detachment, Jakarta, Indonesia

SHILPA HAKRE, MPH, DRPH, Walter Reed Army Institute of Research, Silver Spring, Maryland, USA

SHERI HAPPEL LEWIS, MPH, The Johns Hopkins University Applied Physics Laboratory (JHU/APL), Laurel, Maryland, USA

LOGAN HAUENSTEIN, MS, The Johns Hopkins University Applied Physics Laboratory (JHU/APL), Laurel, Maryland, USA

REKHA HOLTRY, MPH, The Johns Hopkins University Applied Physics Laboratory (JHU/APL), Laurel, Maryland, USA

HAROLD LEHMANN, MD, PHD, The Johns Hopkins University School of Medicine Baltimore, Maryland, USA
KATHY HURT-MULLEN, MPH, Montgomery County (Maryland) Department of Health and Human Services Rockville, Maryland, USA
JOSEPH S. LOMBARDO, MS, The Johns Hopkins University Applied Physics Laboratory (JHU/APL), Laurel, Maryland, USA
WAYNE LOSCHEN, MS, The Johns Hopkins University Applied Physics Laboratory (JHU/APL), Laurel, Maryland, USA
HAOBO MA, MD, MS, Science Applications International Corporation, Atlanta, Georgia, USA
STEVEN MAGRUDER, PHD, The Johns Hopkins University Applied Physics Laboratory (JHU/APL), Laurel, Maryland, USA
COLLEEN MARTIN, MSPH, Science Applications International Corporation, Atlanta, Georgia, USA
SHAMIR NIZAR MUKHI, MSC, Public Health Agency of Canada, Guelph, Ontario, Canada
CECILIA MUNDACA, MD, U.S. Naval Medical Research Center Detachment, Lima, Peru
DAVID ROSS, SCD, Public Health Informatics Institute (PHII), Decatur, Georgia, USA
MARVIN SIKES, MHA, The Johns Hopkins University Applied Physics Laboratory (JHU/APL), Laurel, Maryland, USA
CAROL SNIEGOSKI, MS, The Johns Hopkins University Applied Physics Laboratory (JHU/APL), Laurel, Maryland, USA
NATHANIEL TABERNERO, MS, The Johns Hopkins University Applied Physics Laboratory (JHU/APL), Laurel, Maryland, USA
MICHAEL W. THOMPSON, PHD, The Johns Hopkins University Applied Physics Laboratory (JHU/APL), Laurel, Maryland, USA
JEROME I. TOKARS, MD, MPH, Centers for Disease Control and Prevention (CDC), Atlanta, Georgia, USA
RICHARD WOJCIK, MS, The Johns Hopkins University Applied Physics Laboratory (JHU/APL), Laurel, Maryland, USA

Preface

During the last quarter of the twentieth century, countries with advanced healthcare systems felt comfortable in their ability to manage the spread of diseases that would have had high morbidity and mortality in earlier years. Smallpox had been eradicated and the memory of the Spanish Influenza outbreak of 1918 had faded. Toward the end of the twentieth and into the twenty-first century, the overuse of antibiotics, resulting in disease resistance, the rapid spread of HIV, and the increasing threat of bioterrorism were examples of public health issues that were beginning to increase pressure to enhance existing disease surveillance processes.

Among these concerns, the clandestine release of a deadly pathogen on an unsuspecting population maybe the most insidious public health threat. Most pathogens available as bioweapons can cause high mortality and could lead to the collapse of the healthcare delivery and emergency response systems in an area under attack. The contamination and the possible closure of major medical centers, even if only temporary, would have a serious impact on the health of the population. To mitigate the consequences of this type of public health event, an effective detection and treatment campaign must be launched early in the course of the outbreak.

Because of the threat of bioterrorism and the emergence of new infectious diseases, disease surveillance systems that utilize modern technology are becoming commonplace in public health agencies. The objective of this book is to present the components of an effective disease surveillance program that utilize modern technology. These components include the research, development, implementation, and

operational strategies that are finding their way into successful practice.

Advanced disease surveillance systems automatically acquire, archive, process, and present data to the user. The development and maintenance of the systems require skilled personnel from the fields of medicine, epidemiology, biostatistics, and information technology. In addition, for the surveillance systems to be useful, they must adapt to the changing environment in which they operate and accommodate emerging public health requirements that were not conceived previously.

Research and innovation have led to the implementation of surveillance methods that would have been considered impossible or radical only a few years ago. For example, the case definitions or events under surveillance, which traditionally rely on diagnosis, have been altered in many systems to rely on less specific pre-diagonstic health indicators of syndromes. Correctly filtering data into syndromes or other categories for analysis requires knowledge of the underlying diseases and health-seeking behaviors of the population. Additionally, for analytical tools to have high specificity, they must take into account the normal range of all of the variables that comprise the background for the health indicators. Tools that fuse data and information from inhomogeneous indicators are necessary to provide decision-maker with comprehendable output. Similarly, information technologists must automate data ingestion and cleansing, optimize system architecture, and create user-friendly interfaces while meeting the challenge of using and customizing commercial, off-the-shelf products.

Users’ requirements must have a higher priority than solutions that are technologically exciting. Continuing dialogue must exist among the users and the multidisciplinary development team to establish an effective

surveillance capability that fits within the environment where it will be deployed. Without close interaction between these groups, effective advanced disease surveillance will be compromised. Changes to traditional thinking have resulted in the implementation of improved methods that are more suited to meeting the current challenges facing health departments. Because it is difficult to anticipate future public health emergencies, a continuing adaptation is required to maintain satisfactory system performance.

The field of public health informatics is growing rapidly as applications of technology are being applied to permit health departments to recognize and manage disease in the populations they serve. This book is intended for use (1) as a textbook for public health informatics students, (2) as a reference for health departments that are exploring modern information technology to support their surveillance activities, and (3) as training material for workshops that are components of disease surveillance and public health conferences.

The contents of this book provide insight into not only the technology but also into the difficulties and the successes that the public health community has had with the implementation and operational use of advanced disease surveillance systems. Hence, chapter authors provide not only the views of academics and developers of the technology, but also of users from health departments in the United States, Canada, United Kingdom, South America, and Asia. This wide variety of perspectives will hopefully provide a broad and balanced treatment of issues related to developing and operating advanced surveillance systems.

The book is divided into three parts. Following an introductory chapter (Chapter 1), the first part (Chapters 2 through 5) presents the methods and technologies needed to implement a modern disease surveillance system, including the data sources currently being used in

syndromic surveillance systems (Chapter 2); the mechanisms for the acquisition of data for surveillance systems (Chapter 3); an overview of analytical methods for the recognition of abnormal trends within the data captured for surveillance (Chapter 4); and some basics of systems architectures, text parsing, and data visualization techniques (Chapter 5).

The second part of the book (Chapters 6 through 9) is devoted to case studies of modern disease surveillance systems and provides examples of several implementations in the United States, Canada, Europe, and Asia. These chapters indicate the breadth of the techniques used across the globe in applications of modern technology to disease surveillance.

The third and last part of this book (Chapters 10 through 12) addresses practical questions regarding the evaluation of disease surveillance systems, education of future public health informatics personnel and disease surveillance practitioners, and a look to the future to consider how technology will continue to influence the practice of disease surveillance.

Joseph S. Lombardo
The Johns Hopkins University
Applied Physics Laboratory
Laurel, Maryland, USA

David L. Buckeridge
McGill University
Montreal, Quebec
Canada

Acknowledgments

The chapter authors drew upon their extensive knowledge and experience to make this book a reality. Their contributions have made it possible for this book to include a depth of information on the wide variety of topics needed to implement, operate, and evaluate advanced disease surveillance applications.

In addition to the chapter authors, the talents of several individuals made this book possible. They took time from their busy lives to help assemble and review the materials from the authors. We are indebted to Steve Babin in particular for his knowledge of LaTEX and for the enthusiasm he brought to the project. The book could not have been assembled without the organizational skills of Sue Pagan who converted the diverse materials received from authors into chapters. Evelyn Harshbarger should also be recognized for the conversion of draft figures into high-quality images. Christian Jauvin's help was instrumental in creating the index. Finally, we would also like to thank Judy Marcus for her expert guidance in translating many flavors of jargon into readable material.

Chapter 1

Disease Surveillance, a Public Health Priority

Joseph S. Lombardo, David Ross

Pandemic influenza, West Nile virus, severe acute respiratory syndrome (SARS), and bioterrorism are a few of the current challenges facing public health officials. The need for early notification of, and response to, an emerging health threat is gaining increasing visibility as public opinion increases the pressure to reduce the mortality and morbidity of health threats. With the greater emphasis on the early recognition and management of health threats, federal, state, and local health departments are turning to modern technology to support their disease surveillance activities. Several modern disease surveillance systems are in operational use today. This book presents the components of an effective automated disease surveillance system and is intended for use by public health informatics students, masters of public health students interested in modern disease surveillance techniques, and health departments seeking to improve their disease surveillance capacities.

This introductory chapter provides an overview of the changing requirements for disease surveillance from the perspective of past, present, and future concerns. It includes a brief history of how technology has evolved to enhance disease surveillance, as well as a cursory look at modern disease surveillance technology and activities.

1.1 INTRODUCTION

Control of infectious diseases is a cornerstone of public health. Various surveillance methods have been used over the centuries to inform health officials of the presence and spread of disease. The practice of disease surveillance began in the Middle Ages and evolved into the mandatory reporting of infectious disease cases to authorities responsible for the health of populations.

A common definition of surveillance is “the ongoing systematic collection, analysis, and interpretation of outcome-specific data for use in planning, implementation, and evaluation of public health practice” [1]. One of the more challenging aspects of public health surveillance is the early identification of infectious disease outbreaks that have the potential to cause high morbidity and mortality. In recent years, concern over potential uncontrolled outbreaks due to bioterrorism or the appearance of highly virulent viruses such as avian influenza has placed increased pressure on public health officials to monitor for abnormal diseases. Public concern was heightened when at the beginning of the twenty-first century, the dissemination of a biological warfare agent through the U.S. mail system revealed weaknesses in the ability of existing public health surveillance systems to provide early detection of a biological attack.

Containment of potential outbreaks is also confounded by advances in transportation technology. Modern transportation systems permit communicable diseases to be carried around the world in hours over many public health jurisdictions. Health authorities can no longer simply be concerned only with the health status of the populations they serve; they must also cooperate and collaborate in surveillance and containment activities at regional, national, and international levels.

The Internet is an enabling technology for collaboration across wide geographic areas. Information technology in general is also playing a vital role in the timely capture and dissemination of information needed for identification and control of outbreaks. The subject of this book is the use of modern information technology to support the public health mission for early disease recognition and containment.

1.2 THE EMERGING ROLE OF INFORMATICS IN PUBLIC HEALTH PRACTICE

For more than 50 years, public health has been undergoing a change in identity that strongly affects how the public health sector envisions the use of information technologies. Public health is best viewed as an emergent industry. It has grown from a collection of single-purpose disease prevention and intervention programs to a national network of professionals linked through professional and organizational bonds. The 1988 Institute of Medicine report titled “The Future of Public Health” recognized that public health was established around three core functions and 10 essential services.

The core functions are:

- Assessment
- Assurance
- Policy development

The 10 essential services are:

1. Monitor health status to identify and solve community health problems.

2. Diagnose and investigate health problems and health hazards in the community.

3. Inform, educate, and empower people about health issues.

4. Mobilize community partnerships to identify and solve health problems.

5. Develop policies and plans that support individual and community health efforts.

6. Enforce laws and regulations that protect health and ensure safety.

7. Link people to needed personal health services and assure the provision of health care when otherwise unavailable.

8. Assure a competent public health and personal health care workforce.

9. Evaluate effectiveness, accessibility, and quality of personal and population-based health services.

10. Research for new insights and innovative solutions to health problems.

Information is one of the central products produced by public health. Protecting community health; promoting health; and preventing disease, injury and disability require vigorous monitoring and surveillance of health threats and aggressive application of information and knowledge by those able to prevent and protect the public's health. Thus, public health *informatics* supports the activities, programs, and needs of those entrusted with assessing and ensuring that the health status of entire populations is protected and improves over time.

Public health informatics has been defined as the systematic application of information and computer science and technology to public health practice [2]. The topic supports the programmatic needs of agencies, improves the quality of population-based information upon which public health policy is based, and expands the range of disease prevention, health promotion, and health threat assessment capability extant in every locale throughout the world [3]. In

Diagnosis
Disclosure
Disease control

EARS
Edgington
Emergency department
Emerging infectious disease
EMS
Encryption
Epidemic
Epidemiology
Error
Essential services
Evaluation
Event detection
EWORS
False alarm
Fever
Firewall
Florence Nightingale
Flu
Forecasting
Free-text data
FTP

Gastrointestinal syndrome group
Geographic information system

Healthcare information technology standard panel
Health department
Health Protection Agency
Health-seeking behavior
HIPAA
HITSP

HL7
HMO

ICD-9 code
ILI
Incubation period
Indicator
Individually identifiable health information
Infectious disease
Influenza
Informatics
Injury
Institute of Medicine
Interface
International health regulation
Internet
Interoperability

Laboratory test
Latency
Line listing
Linux
LOINC

Mapping
Medical informatics
Medical record
Medicare
Moving average
Multivariate
MySQL

National electronic disease surveillance system
National enteric surveillance program
National syndromic surveillance conference

NCR
Network
NHS direct
Notifiable disease
Null hypothesis

OTC
Outbreak

Pandemic
Password
Pathogen
PCR
PDA
Permissible disclosure
PHI
PHIN
Pneumonia
Pollen
Prescription
Prevention
Preventive medicine
Privacy rule
ProMED
Public health authority
Public health informatics
Public health informatics institute
Public health information network
Public health intelligence
Public health response
Public health service

Qualitative data

Real-Time Outbreak Detection System

Regional health information organization
Regression
Reportable disease
Resource-poor setting
Respiratory
Response protocol
ROC
Rotavirus

SaTScan
Scan statistics
School absenteeism
Security
Sensitivity
Sentinel surveillance system
Simulation
Situational awareness
Smallpox
Spatial information
Specificity
SQL
Stratification
Surveillance system
Syndromic surveillance
System administration
System architecture
System evaluation
System flexibility

Telephone triage
Thick client application
Threshold
Time lag
Timeliness