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Acknowledgements

In September 2004, the Council of State and Territorial Epidemiologists (CSTE) published a white paper entitled Essential Functions of Chronic Disease Epidemiology in State Health Departments by the Chronic Disease Epidemiology Capacity Building Subcommittee. Then in 2008, CSTE published The New State Epidemiologist’s First Days: a Planning Guide. More recently, the CSTE Chronic Disease Epidemiology Capacity Building Subcommittee saw the need for a separate planning guide and orientation manual for the chronic disease epidemiologists in state and local health departments. This manual is the result of the Subcommittee’s work and highlights information and resources that an applied chronic disease epidemiologist will need to use regularly.

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Chapter 1: Introduction

Definition of Chronic Diseases
Chronic diseases—heart disease, cancer, diabetes, arthritis, stroke, chronic lower respiratory disease, and others—are illnesses that persist over time, can gradually progress, do not resolve spontaneously, and may not be cured. They are leading causes of morbidity, mortality, disability, and decreased quality of life in the United States.\(^1\) Chronic diseases account for at least 65% of all deaths, and about 84% of health spending in the United States.\(^2,3\) One out of four Americans have multiple chronic conditions,\(^3\) with hypertension being the most common condition among Medicare beneficiaries with multiple conditions.\(^4\) Additionally, chronic diseases are responsible for the widest health disparity gap among racial/ethnic groups in the United States. While chronic diseases are prevalent, costly, and potentially debilitating or fatal, they and/or their sequelae are, in part, preventable. Preventing chronic diseases is challenging due to a complex etiology: the interaction of genetics, cumulative behavior, and socio-political and physical environment. Chronic diseases can be characterized by uncertain etiology, multiple risk factors and a prolonged, progressive disease course that aging exacerbates. However, many known risk factors for chronic diseases, such as smoking, unhealthy diet, and physical inactivity, are amenable to change through interventions targeting individuals and communities.

Changing Patterns and the Need to Focus on Chronic Disease
In 1900, three groups of illnesses—(1) pneumonia and influenza; (2) tuberculosis; and (3) gastritis, enteritis and colitis—accounted for nearly one third of all deaths.\(^5\) However, public health and medical advances helped to prevent and control these conditions and contributed to an increase in life expectancy in the developed world. These factors, along with the aging of the population, have led to an increase in the number of U.S. residents living with one or more chronic diseases.\(^6\)

Today, heart disease, cancer and stroke account for over half of all deaths—the result of an epidemiologic transition from acute infectious diseases to noninfectious chronic diseases as the

\(^1\) CSTE. Essential Functions of Chronic Disease Epidemiology in State Health Departments. 2004.
predominant causes of morbidity and mortality, a transition described over 40 years ago.\textsuperscript{7} Ironically, the epidemiologic transition has been driven by the very technologic and economic developments that have contributed to longer lives. The transition shifts the primary focus of healthcare from treating acute, infectious diseases to modifying risk factors to prevent and control chronic diseases.

The Institute of Medicine described the mission of public health as assuring conditions in which people can be healthy.\textsuperscript{8} In 1988, the Centers for Disease Control and Prevention (CDC) established the National Center for Chronic Disease Prevention and Health Promotion “to create expertise, information, and tools to support people and communities in preventing chronic diseases and promoting health for all.”\textsuperscript{9} With this mission to assure healthy conditions and promote health for all and with focused funding from CDC, many states have strengthened their chronic disease programs to support sound data-driven policies and public health interventions. Epidemiology is a central component of these efforts.

Public health departments prioritize problems that lead to illness, disability, or death (measured by their high prevalence or high fatality rate), that result in high health care cost, and/or that reduce quality of life. Chronic diseases in the population meet all three criteria of public health importance. Therefore, public health departments need to address chronic disease by increasing their number of chronic disease epidemiologists and by supporting at least one lead chronic disease epidemiologist to oversee and coordinate data collection, analysis, interpretation, and translation of data and research to public health practice.\textsuperscript{10}

**Role of Chronic Disease Epidemiology**

Epidemiology is the “study of the distribution and determinants of health-related states in specified populations, and the application of this study to control health problems”.\textsuperscript{11}

In the case of infectious diseases, the presence of specific causative agents helps epidemiologists focus on host-agent-environment interactions and recommend interventions to prevent and control the diseases, especially during outbreaks of acute illness. Chronic diseases, which are not chronic infectious diseases such as HIV or tuberculosis, often have multi-factorial origins and complex determinants that play out over a lengthy time period.

The nature of chronic illness dictates that chronic disease epidemiologists understand all three stages of disease prevention. \textit{Primary prevention} focuses on protecting healthy individuals from developing disease or experiencing injury with a focus on reducing risk factors and increasing protective factors in individuals across a population. \textit{Secondary prevention} aims to prevent the

\textsuperscript{7} Omran AR. The epidemiologic transition. \textit{Milbank Mem Fund Q.} 1971; 49(4):509-38.


\textsuperscript{10} CSTE. Essential Functions of Chronic Disease Epidemiology in State Health Departments. 2004.

onset of symptoms in the earliest stages of disease once an illness or risk factors have been diagnosed or identified. **Tertiary prevention** deals with minimizing the negative effects of disease and preventing disease-related complications, total disability, and premature death by improving healthcare quality and individuals' management of complicated, long-term health problems.

In brief, the role of the chronic disease epidemiologist is to collect, analyze, synthesize, and disseminate disease-specific information—medical, societal and financial costs, spatial and temporal disease distribution, and risk factors or causes—so that the epidemiologist can:

- Assess the burden of chronic diseases across the lifespan.
- Inform policies and evidence-based programmatic activities to prevent and control chronic diseases.
- Promote collaborations with peer colleagues to address age-related chronic disease issues (e.g., the life span approach), health disparities, social determinants of disease, and health inequities.

In addition to these functions, chronic disease epidemiologists play a significant role in enhancing efficiency, focusing (or refocusing) public health program efforts, and allocating scarce resources.

**Purpose of a Chronic Disease Epidemiologist Orientation Manual**

Commonly, state chronic disease epidemiologists serve one categorical program, such as tobacco, or cancer. However, with recent and ongoing efforts to integrate and coordinate across and chronic disease programs, the role and influence of a chronic disease epidemiologist will broaden to address multiple program areas.

This manual is intended to serve as a “quick start” menu of resources for lead chronic disease epidemiologists working in state, territorial, tribal, or local health departments. Such an epidemiologist can demonstrate mid-level competencies in epidemiology, also known as CSTE Tier 2 competencies.12 This epidemiologist might serve as the sole epidemiologist in the chronic disease program or as the lead chronic disease epidemiologist (the single point of contact for chronic disease epidemiology) responsible for coordinating or integrating chronic disease epidemiology activities across categorical programs. Throughout its chapters, this manual uses “lead chronic disease epidemiologist” to refer to this main target audience. This manual provides a road map and advice for serving in this capacity or role as the “lead chronic disease epidemiologist.”

Additional intended audiences and uses of the information and guidance in this manual include:

- Local epidemiologists who serve in a variety of capacities, including addressing chronic disease issues;
- Senior epidemiologists or senior professionals who hire, train, and/or mentor chronic disease epidemiologists;

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• Entry-level chronic disease epidemiologists (CSTE Tier 1) who might focus on one disease and/or one type of data source and who is interested in increasing their knowledge and understanding of potential next steps in career development;
• Recent graduates in chronic disease epidemiology who have limited applied experience in a state public health department; and
• Epidemiologists with experience at state health departments but who are new to chronic disease prevention.

However, this manual is not everything to everyone and is not intended to be a comprehensive epidemiology manual. Still, it is the authors' hope that this manual will encourage discussion and collaboration to address challenges and spur innovation in the delivery of data-driven chronic disease epidemiology services throughout the United States.

**Organization of the Chronic Disease Epidemiologist Orientation Manual**

**Chapters 2 through 8** begin with a brief description highlighting the relevant content for each level of epidemiologist, based on CSTE Tiers 1-3 of epidemiology competencies. A summary at the end of each chapter organizes the main points related to the three essential public health services in which epidemiologists are leaders:\(^\text{13}\)

1. Surveillance
2. Communication
3. Consultation

If applicable, summaries will include main points related to evaluation, because there is a growing need for epidemiologists to respond to impact and accountability requests Therefore, chronic disease integration elevates the need for epidemiologists to develop and measure SMART objectives (i.e., objectives that are specific, measurable, achievable, realistic, and time-phased) and performance measures that demonstrate accountability to funders and provides data to constituencies. Measuring the impact of an integrated program on the prevalence of a specific chronic disease (or its risk factors) will meet the needs of the categorical funders and constituent groups.\(^\text{14}\) **Chapter 9 describes technical assistance** offered by professional organizations and public health agencies that fund, provide training and technical assistance, and build workforce capacity. The last chapter, the **Summary Chapter**, is divided into two parts. The first part lists key points from this manual for the 1st week, 1st month, 1st 90 days, and 1st year. The second part shows the relationship between the essential public health services, the responsibilities of a lead chronic disease epidemiologist, and the chapters in this manual. **The Appendices** provide links to additional resources and useful details, such as common acronyms, disease and procedure codes used in health care claims data, useful SAS statistical code

\(^{13}\) CSTE. Essential Functions of Chronic Disease Epidemiology in State Health Departments. 2004.

for using data from the Behavioral Risk Factor Surveillance System, position descriptions, and more.

Below is a suggested timeline for using this manual and for activities related to building your competency and your relationships with your supervisor, colleagues, and partners.

**In the first week**

- Read Chapter 2: Understanding the Job.
- Copy the checklist in Table 2-1 into an electronic document. Use it to keep track of your ideas and personal action items that you identify as you read through the rest of the manual.
- Share a copy of the checklist in Table 2-1 with your supervisor.
- Ask for and collect or bookmark the documents and resources listed in Table 2-1 (the checklist).

**In the first month**

- Read Chapter 3: Chronic Disease Integration. Ask your supervisor to read and discuss it.
- Meet with key staff and colleagues within the department.
- Read through the documents and resources that you have collected.

**In the first quarter**

- Complete a self assessment of your competencies, using the CSTE tool, and share with your supervisor.
- Share your ideas and personal action items with your supervisor and ask him or her to prioritize them based on relevancy to your current job.
- Develop individual goals for the first year based on the self assessment and input and direction from the senior epidemiologist and your supervisor.
- Read Chapter 4: System Approaches and Social Ecological Model, Chapter 5: Evidence-based Public Health, and Chapter 6: Data Governance.
- Read additional chapters and related appendices based on the assessment and input.

**In the first six months**

- Read Chapter 7: Surveillance—Data Sources and Indicators, Chapter 8: Data Interpretation and Dissemination, and Chapter 9: Technical Assistance and Related Programs, if you have not already read the full chapters.
- Discuss long-term goals for the work and for your career with your supervisor.

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In the first year

- Meet with key external partners.
- Attend at least one meeting of every coalition or stakeholder group.
- Use the manual as a starting place for any new topic or new assignment, so that you are aware of the resources and information already available to you. Search the manual for keywords related to the topic or assignment.
- Submit an abstract for presentation at the annual conference of CSTE, a national or state public health association, or a CDC-sponsored conference.
- Consider setting up a learning community to share with colleagues and partners information from this manual or the many resources on the web cited in this manual. Exchange real-world examples and learn from each other.
Chapter 2: Understanding the Job

This chapter discusses the roles and responsibilities of a chronic disease epidemiologist at a state or large local health department and shares resources to help you fulfill the roles and responsibilities. As a lead epidemiologist with experience at a state health department yet new to integrated chronic disease prevention, being successful in your job demands being collaborative across organizational boundaries to address the complexities of multiple chronic diseases. You will need to build new working relationships quickly, enhance your communication and consulting skills, assess your developmental areas and set related growth goals, and seek professional mentoring beyond your direct supervisor. With these activities in mind, read this chapter. For the senior epidemiologist or senior professional who supervises or mentors the lead epidemiologist, you can use this chapter to orient the new lead chronic disease epidemiologist to the broad context of the job and to identify relevant reading and key people to meet. Think about how long it took you to learn how the organization really works, review the list of resources at the end and highlight the topics most valuable to your new chronic disease epidemiologist. For the entry-level epidemiologist interested in increasing your knowledge and understanding of potential next steps in career development, read the section on setting goals for your position and click on the resource link for a capacity assessment.

Know the Chronic Disease Epidemiologist’s Public Health Roles

As outlined in a 2004 CSTE white paper, Essential Functions of Chronic Disease Epidemiology in State Health Departments, the essential functions include, but are not limited to:

Surveillance:
- Collecting, analyzing, and interpreting chronic disease surveillance data to assess the burden of chronic disease and provide information on the distribution and risk factors of chronic diseases necessary for public health program planning and implementation
  - Coordinating and evaluating chronic disease surveillance, according to nationally developed standards, including establishing and following data use agreements.
- Assisting in the evaluation of public health programs.
- Monitoring compliance of chronic disease reporting, if mandated by Board of Health rule.

Communication:
- Disseminating results of chronic disease surveillance regularly and widely in a variety of formats to support science-based decisions about health issues by policy-makers, programs leaders, and the general public.

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16CSTE. Essential Functions of Chronic Disease Epidemiology in State Health Departments. 2004.
• Serving as the state’s point of contact with CDC's National Center for Chronic Disease Prevention and Health Promotion and CSTE as it relates to chronic disease epidemiology.
• Assuring that documents produced by chronic disease programs—reports, grants, and cooperative agreement applications, press releases—receive appropriate epidemiology input.

Consultation:
• Providing decision-makers with information necessary for planning, implementing and evaluating public health programs and policies, and for establishing goals and priorities related to chronic disease.
  o Providing appropriate epidemiology technical support to state chronic disease programs. This includes (1) epidemiology capacity/activities are coordinated across individual, categorical chronic disease programs, (2) community health assessment activities related to chronic disease control are coordinated at the state level, and (3) chronic disease programs are evaluated on a regular basis.

Capacity building:
• Monitoring the adequacy of the state’s chronic disease epidemiology capacity at least every two years and updating it as appropriate and feasible.
• Maintaining a state strategic plan for filling gaps identified during the capacity assessment process.

Although CSTE recommends these functions for a central, coordinating chronic disease epidemiologist position in a state health department, referred to as the lead chronic disease epidemiologist in this manual, chronic disease epidemiologists at various levels would benefit from understanding the role of the lead chronic disease epidemiologist and how that may differ from other chronic disease epidemiologists in their agency. A key function reserved solely for the lead chronic disease epidemiologist is the coordination and integration of chronic disease epidemiology activities across categorical programs. This function is so important that CSTE recommends that the minimum work force in chronic disease epidemiology include at least one epidemiologist responsible for overall coordination across chronic disease program areas among a minimum of five chronic disease epidemiologists total.\(^\text{17}\)

The functions of a lead chronic disease epidemiologist fall within CDC’s ten essential public health services, depicted in Figure 2-1.\textsuperscript{18}

**Figure 2-1. The three core functions of public health and related ten essential public health services.**

Chronic disease epidemiologists are critical to delivering three of the ten essential services:
1) monitoring health status to identify and solve community health problems (surveillance),
2) informing, educating and empowering people about health issues (communication) and
3) developing policies and plans that support individual and community health efforts (consultation).\textsuperscript{19}

In contrast, chronic disease epidemiologists play a "supportive or coordinating role" evaluating population-based health services, assuring a competent public health and personal health care workforce, and diagnosing and evaluating community health problems and hazards. The remaining essential public health services—research, enforcement of public health laws and regulations, and linking people to healthcare providers—require limited involvement from the state chronic disease

\textsuperscript{19} CSTE. Essential Functions of Chronic Disease Epidemiology in State Health Departments. 2004.
epidemiologist. In addition to prioritizing the ten essential public health services, the CSTE white paper further describes each role and associated duties and provides examples from state health departments.

These roles can follow a sequence (and cycle) comprising an evidence-based approach to public health planning:

1) Assess community health problems,
2) Quantify the issue(s),
3) Develop a concise statement of the issue(s) and potential strategies,
4) Determine what is known from the scientific literature,
5) Develop and prioritize program and policy options,
6) Develop an action plan and implement interventions, and
7) Evaluate the programmatic or policy interventions. (See Chapter 5: Evidence-Based Public Health for more information.)

An evidence-based public health approach (Chapter 5) is particularly important in the face of limited resources, as it identifies interventions with the greatest reach or impact. Moreover, evaluations can assess cost-effectiveness. This approach helps to identify and state mutual benefits and opportunities across disease categories, engage stakeholders, mobilize leaders, and evaluate the intervention, all principles of integration. It can also result in collective impact, the potentially larger impact that occurs when multiple agencies commit to a shared agenda, pursue activities that reinforce each other’s work, and measure their efforts. The evaluation of the policy or public health intervention becomes even more important when integrating chronic disease programs. To keep the support of the funders, experts, and constituencies of a single chronic disease area, integrated programs will still need to demonstrate the progress and impact of addressing common risk factors or multiple outcomes through the policy or public health intervention.

Learn All About Your Organization

As a new chronic disease epidemiologist in a leadership position, one of your first tasks is to understand the organizational context of your position; that is, your role within your program, your program’s role within the health department and the health department’s role vis-à-vis other state and local agencies. Although state chronic disease epidemiologists share similar responsibilities, the chain-of-command and specific job expectations may vary from health department to health department. Therefore, it is important to know your health department well.

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Here are some important first steps in understanding the organizational context of your new job:

- Review the health department’s strategic plan and mission, and vision statements.
- Review the health department’s and the division’s organizational charts and decision-making authorities.
- Review the health department director’s priorities.
- Inquire about the health department’s relationships with other agencies, including local public health agencies and relevant federal agencies.
- Ask about local public health agencies’ roles and their expectations from the state health department.
- Understand the department’s funding and your program’s grants, budget, and fiscal calendar.
- Review existing and preferred communications procedures.
- Review previous press releases, media policies and the approval process for talking to the media.
- Review the policy for releasing reports with the department’s name or logo on it.
- Learn how the health department accesses full-text peer-reviewed publications.
- Develop relationships with your colleagues across the division and department. (See also Chapter 3: Chronic Disease Integration and Collaboration.)
- Ask colleagues to identify the external experts and constituencies in the categorical areas of chronic disease.
- Inquire about the primary challenges for your program/branch/division, including disease burden, resource limitations, and political challenges.
- Learn about data governance within the department (Chapter 6), including the privacy and security board, data sharing agreements, data access policies, data release/data suppression policies, Board of Health rules related to reportable conditions that are chronic diseases, and the IRB’s role.

Meet With Your Colleagues across the Division and Department

Relationships with division and departmental colleagues are crucial to effectively carry out the work of a state chronic disease epidemiologist. Possible colleagues include:

- Other chronic disease epidemiologists.
- Chronic disease program managers and staff.
- Maternal and child health, oral health, injury, mental health, substance abuse, environmental health, occupational health, and communicable disease program managers, staff, and epidemiologists.
- Division leaders.
- Statisticians and data managers, including staff who manage/coordinate vital statistics data, hospital discharge data, and data from major surveillance systems, such as the Behavioral Risk Factor Surveillance System (BRFSS) and Youth Risk Behavior Surveillance System.
(YRBSS). (It is especially important to build a relationship with the BRFSS coordinator. Some of these persons might be in other organizations, for example, the state department of education.)

- Communications staff, including the department’s public information officer.
- Administrative staff.

Build relationships with these colleagues. Understand their roles and how you can assist each other for an efficient use of staff, funds, and surveillance and intervention efforts. Ask. Listen.

Table 2-1 comprises a simple checklist to help you keep track of documents and other information your colleagues share with you during the orientation period.

**Table 2-1. Checklist for Sharing Documents, Resources, and Information during Orientation.**

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<td>Program Area-Specific Info</td>
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<td>Statewide plans</td>
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<td>Contact info for personnel, contractors</td>
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<td></td>
<td>Copies of grants, budgets, work plans</td>
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<td>Copies of cooperative agreements</td>
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<td>Data sharing agreements</td>
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<td>Data products (fact sheets, reports)</td>
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<td>Epidemiologist job description</td>
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<td>Suggested Resources</td>
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<td>Other training materials/resources</td>
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<td>Articles/other resources</td>
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<tr>
<td>Upcoming Events</td>
<td>Calendar—important dates</td>
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<td>Appropriate conferences (dates)</td>
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<td>Program Area Communication</td>
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Develop Short- and Long-term Goals for Your Position

The development of short- and long-term goals will help to focus your efforts and provide a means to gauge progress. Start by reviewing existing work plans and clarifying the needs of the program/branch/division. Learn about the health status of state residents, including social determinants of health and any changing demographic characteristics of the state population.

Specific goals could include time-bound objectives for providing technical assistance to program staff and other epidemiologists, assessing epidemiology capacity and creating a capacity-building plan, evaluating current surveillance systems, and developing policies and procedures.22 A short-term goal for your position could be to find and review a cost-benefit analysis of the Stanford chronic disease self-management course. A long-term goal could be to communicate this analysis to the state legislative committee hearing a bill to expand funding for the Stanford chronic disease self-management course or to conduct a cost-benefit analysis of adding an evidence-based fall prevention component to this course. Another long-term goal for your position is to make the case for expanding the number of chronic disease epidemiologists in your organization or to expand their capacity.

Expanding Chronic Disease Epidemiology Capacity

Conducting a formal epidemiology capacity assessment is a good first step to document and address limited capacity or limited public health training of chronic disease epidemiology staff. CSTE’s Applied Epidemiology Competencies Toolkit defines competencies for four tiers of practicing epidemiologists and provides competency assessment forms for each.23

CSTE’s 2009 report on the national assessment of chronic disease epidemiology capacity recommends that all state-level chronic disease epidemiology programs maintain minimum staffing levels and have access to key tools and other resources to support their work:24

- A designated coordinating/lead chronic disease epidemiologist and a minimum of five full time chronic disease epidemiologists, including at least one with doctoral-level training.
- Ability to access and analyze key datasets in timely fashion, including state mortality data, hospital discharge data, tumor registry data, BRFSS data, emergency department/emergency medical services (EMS) data, and Medicare data. (Because mortality and Medicare data have been problematic of late, they may require special attention.)
- Ability to calculate confidence intervals for BRFSS prevalence estimates and death rates.
- Easy access to medical journals.
- Adequate information technology (IT) and clerical support services.

22 CDC. Chronic Disease STEPPS—State-based Epidemiology for Public Health Program Support. Atlanta, GA. (Document available from program staff at the National Center for Chronic Disease Prevention and Health Promotion.)
• Access to geographic information system (GIS) software for analysis of spatial aspects of chronic disease, including routine geocoding of population-based, chronic disease data that lends itself to geocoding, beginning with birth and death data.

Build Partnerships with Communities, Academia, and Other Agencies

Developing strategic partnerships with communities, academia, and other government agencies can help you meet your goals. For every issue you address, you will find people with mutual interests and concerns. Undoubtedly, you will find that nurturing relationships takes time and energy. It is worth the effort. Meeting with constituents on their territory—at their offices, community centers or staff meetings—is a gracious and appreciated gesture of interest and sincerity. You should consider establishing relationships with appropriate stakeholders in community health centers, professional associations, and other state agencies, as they may be important allies.25 CSTE recommends state chronic disease epidemiologists maintain strong relationships with key partners to promote efficient use of resources, enhance surveillance, and plan and implement evidence-based strategies for chronic disease prevention and health promotion.26 It singles out three classes of partners:

• Substance abuse, mental health, and public health preparedness epidemiologists. (In the absence of state-level substance abuse and/or mental health surveillance capacity, chronic disease programs should consider incorporating substance abuse and mental health surveillance into their surveillance activities, as these are major public health issues during disasters, and chronic disease epidemiologists should be prepared to assist during public health emergencies.)
• Local academic programs.
• Other state health agencies.

Academic leaders of schools of public health and colleges of medicine, nursing, and allied health professions can be important allies, as well. Many chronic disease epidemiologists are guest lecturers or adjunct faculty in public health graduate programs. Academic appointments may come with access to on-line libraries, current public health journals, and other resources and services. Fellow faculty members, for example, can often offer research expertise and consultation. Your establishing relationships with schools of public health can open up opportunities for student internships and practicum projects at the public health department. And continuing education programs can bolster the professional development of your staff. There are many potential opportunities for joint ventures.

Similarly, within the health agency, you want to be viewed as an integral part of the team. Make time to attend meetings and serve on interdepartmental committees. Some of the relationships you form will be vital to mutual success.

Become Active in Local and National Organizations
Give and get support. Help shape the national public health agenda by becoming active in local and national organizations. Volunteer for committee assignments and other leadership positions related to your specialties and interests in national public health and professional organizations, such as the American Public Health Association, and CDC. In addition, familiarize yourself with the work of your local public health directors organization, join your state public health association, and join coalitions (e.g., the state cancer coalition) related to your areas of interest and responsibility.

Join the Council of State and Territorial Epidemiologists (CSTE)
CSTE offers both leadership opportunities and a network of peers who can offer their own best practices and lessons learned from challenges similar to those you face. CSTE are the leaders in applied epidemiology and surveillance who build the future leaders. CSTE serves as the professional nexus of practicing epidemiologists from local and tribal organizations, from state and territories across multiple specialties within epidemiology: chronic disease, infectious disease, oral health, maternal and child health, substance abuse, occupational, environmental, and injuries. Where else can epidemiologists tackle together cross-cutting or emerging issues that span any single funding source or funding agency? You as a lead epidemiologist can benefit from and contribute to:

- Professional development and training via webinars, toolkits, and conferences
- Leadership opportunities, including eligibility to represent CSTE on external consultations and workgroups
- Position statements
- News and information on current public health issues, including an online subscription to the Journal of Public Health Management and Practice and the CSTE quarterly newsletter
- Advocacy on national policies and issues affecting epidemiology and surveillance

This manual uses previous work of CSTE. So as you read this manual, you will see the valuable resources that CSTE creates. Chapter 9 has additional information about CSTE and its fellowships.

Resources
More in-depth information on topics in this chapter is available at the following Web sites.
10 Essential Public Health Services


Epidemiologists’ Roles and Responsibilities

- **CDC/CSTE Applied Epidemiology Competencies Toolkit**: Available at the CSTE Workforce: Competencies Web site. [http://www.cste.org/group/CSTECDCCAEC](http://www.cste.org/group/CSTECDCCAEC) This toolkit includes a joint CDC & CSTE letter, the complete and short summaries of applied epidemiology competencies, competency assessment forms for each tier, sample position descriptions, and more.

Capacity Building

- **CSTE Epidemiology Competency Assessment Forms**: [http://www.cste.org/group/CSTECDCCAEC](http://www.cste.org/group/CSTECDCCAEC)
  These forms are can be used to evaluate one’s level of understanding and ability to perform the competencies at the following levels or tiers:
  - Tier 1: Entry level or basic epidemiologist
  - Tier 2: Mid-level epidemiologist
  - Tier 3a: Senior-level epidemiologist – Supervisor and/or manager
  - Tier 3b: Senior scientist or subject area expert
- **CSTE Epidemiology Capacity Assessments**: [http://www.cste.org/group/ECA](http://www.cste.org/group/ECA)

Evaluating Surveillance Systems

**CDC’s Updated Guidelines for Evaluating Public Health Surveillance Systems**: [http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5013a1.htm](http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5013a1.htm). Evaluating surveillance systems is
important to assess attributes of the systems and their usefulness, and to identify important data gaps.

**Chronic Disease Program Integration**


**The Community Toolbox** (offering nearly 300 topics with practical guidance for community-building)

- **Logic Models**: [http://ctb.ku.edu/en/tablecontents/sub_section_main_1877.aspx](http://ctb.ku.edu/en/tablecontents/sub_section_main_1877.aspx)

**Become Active in National Organizations**

- **American Public Health Association Epidemiology Section**: [www.apha.org/apha-communities/member-sections/epidemiology](http://www.apha.org/apha-communities/member-sections/epidemiology) Association of Maternal and Child Health programs: [www.amchp.org](http://www.amchp.org)
- **Association of State and Territorial Health Officials**: [www.astho.org/](http://www.astho.org/)
- **CDC Chronic Disease Prevention and Health Promotion**: [www.cdc.gov/chronicdisease/index.htm](http://www.cdc.gov/chronicdisease/index.htm)
- **Council of State and Territorial Epidemiologists**: [www.cste.org](http://www.cste.org)
- **National Association of Chronic Disease Directors**: [www.chronicdisease.org/](http://www.chronicdisease.org/)
Summary

This chapter provides a broad overview and context for your job. The main points related to the three public health essential services that epidemiologists provide:

- **Surveillance**: Your role is to coordinate and conduct chronic disease surveillance, including identifying risk and protective factors at the individual and population level and their relationship to the system level. You will disseminate results of chronic disease surveillance regularly and widely in a variety of formats.

- **Communication**: Your role is to communicate scientific and technical information in a way that decision makers can use it. As the lead chronic disease epidemiologist, you might serve as the single point of contact for chronic disease epidemiology in your department and with CSTE, CDC’s National Center for Chronic Disease Prevention and Health Promotion, and the National Association of Chronic Disease Directors.

- **Consultation**: It is often through your consultation that you connect the science and data to the policy options and policy makers in your state. Ideally, you will consult on any chronic disease project early to ensure data-driven action. Specifically, your consultation is to (1) assure that reports, grants, and cooperative agreement applications receive appropriate epidemiology input, (2) coordinate across individual, categorical chronic disease programs, (3) connect state activities with state community health assessment, and (4) infuse evaluation into chronic disease programs and monitor the evaluation results.
Chapter 3: Chronic Disease Integration and Collaboration

Various definitions of chronic disease collaboration and integration exist. One oft-quoted definition of integration is “the strategic alignment of chronic disease categorical program resources to increase the effectiveness and efficiency of each program in a partnership, without compromising the integrity of categorical program objectives.”

Regardless of the precise definition used, the goals of chronic disease integration include, but are not limited to:

- Stimulating learning and capacity building (including having staff members learn about other programs in more depth).
- Increasing efficiency and effectiveness (e.g., by sharing and maximizing resources).
- Expanding the reach of programs and communications, particularly to reach underserved and high-risk populations.
- Encouraging dissemination of scientific knowledge, experiences and best practices.
- Instituting changes without increasing burden on partners.

As seen in the textbox example, opportunities for integration among public health programs abound.

Some general examples of integration efforts include:

- Developing integrated state plans.
- Implementing integrated interventions.
- Collaborating on policy, systems, or environmental change efforts.
- Collaborating on funding applications.
- Collaborating on funding announcements.

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An Opportunity for Coordination: Combining Cardiovascular Health & Physical Activity

A Cardiovascular Health Unit is working extensively with the African American community to educate, prevent, and treat hypertension. Yet, the Physical Activity and Nutrition Unit in the same health department has virtually no contacts within this population and has been at a loss to get its message across, despite spending significant resources. Can the two units devise a cost-effective—even cost-saving—strategy to work together to jointly advance the effectiveness of their own programs?


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- Aligning policies and programs.
- Developing a common set of chronic disease indicators and corresponding data dictionary, a common reporting format (e.g., fact sheet template), and a common distribution list for chronic disease communications.
- Integrating the content of data reports across diseases, conditions, and risk factors.
- Integrating funding for communication efforts.
- Enhancing collaboration with external partners.
- Sharing staff across programs (i.e., developing job descriptions that include responsibilities for more than one program).
- Conducting cross-program competency assessments, trainings, and learning communities (i.e., groups of people who actively engage in learning from one another);
- Using common evaluation methodologies across programs.
- Sharing lessons learned across programs.

**Recognize Opportunities for Program Integration**

Chronic disease integration and collaboration can occur across all chronic disease-specific programs and with other programs, such as Maternal and Child Health, Oral Health, Violence and Injury Prevention, Mental Health, Substance Abuse, Environmental Health, Occupational Health, and Communicable Disease.

For instance, recognizing the opportunities for collaboration with Maternal and Child Health Programs requires an understanding of the roles and responsibilities of epidemiologists working in this field. Maternal and child health epidemiology often focuses on women from pregnancy through the postpartum period and on children from birth through adolescence. However, the field of maternal and child health epidemiology is broad and encompasses multiple sub-disciplines focused on the myriad infectious and chronic diseases that occur among women of reproductive age (15–44 years) regardless of their pregnancy status. As such, there is a natural intersection between chronic disease and maternal and child health epidemiology, illustrated by the *life course approach* to public health. Women of reproductive age experience the onset of chronic disease as well as the underlying causes of inherent, latent chronic disease. Working together in areas such as diabetes (including gestational and Type 2 diabetes), hypertension, and heart disease, chronic disease and maternal and child health epidemiologists can monitor the development and progression of disease patterns. Both disciplines can then focus on primary prevention efforts targeting women of childbearing age populations. To do so, however, both chronic disease and maternal and child health epidemiologists must recognize commonalities in their respective responsibilities:

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• Monitoring health status, risk indicators, and health service usage, especially preventive services.
• Investigating determinants and distribution of adverse conditions, risks factors, and adequate health care utilization.
• Developing surveys and surveillance systems.
• Conducting needs assessments.
• Performing process and impact evaluations of programs and policies.
• Assessing program performance.
• Conducting quality assurance activities, including analyses and training.
• Studying funding and costs, (e.g., service cost-benefit and efficiency analyses).
• Inventorying available service resources.
• Providing information and analyses for resource allocation decisions.

These commonalities could lead to endless opportunities for the two programs to learn from one another to improve health outcomes at the population level. Similar lists could be constructed for other public health programs. In all cases, enhancing collaboration across specialty areas, while committing to continuously learning the specifics within each area of interest, furthers the field of epidemiology as a whole.

Learn from Other States
States have recent collaborative efforts between diabetes, tobacco, obesity, aging and disability, cancer control, and oral health programs to collect and use data on the oral health of persons with diabetes and/or tobacco users, oropharyngeal cancer and human papillomavirus, obesity prevalence among children, and health risk factors among seniors. These programs have also collaboratively shared staff.

• Many states use the Behavioral Risk Factor Surveillance System to collect and analyze data on the oral health of persons with diabetes and/or tobacco users. For example, in 2012, one state expanded their surveillance system to assess if persons with diabetes get appropriate dental care services and if persons who smoke tobacco report that dentists encouraged them to stop smoking.
• States have made their results publicly available by publishing fact sheets on oral health among persons with diabetes and/or oropharyngeal cancer and human papillomavirus.
• Several states have collected body mass index (BMI) data to assess obesity rates among Head Start children as part of the Basic Screening Survey administered by the oral health program, and many states have also collected BMI data as part of their Basic Screening Survey of kindergarten and grade school students.
• The oral health program and the aging and disability program in one state have collaborated to expand their oral health assessment on seniors to ask about health risk factors.
• Leveraging partnerships for disseminating and using data to drive action, one state is planning to develop standardized chronic disease data results in a user-friendly format for county
medical officers to present with broad audiences at town hall meetings.

- Some states share epidemiology and/or evaluation staff between programs, such as the oral health and heart disease and stroke prevention programs.

Think about the Multiple Chronic Conditions Framework and Initiative

The U.S. Department of Health and Human Services recognizes the large proportion of persons with multiple chronic conditions, its toll on quality of life, and on health care costs.\textsuperscript{29} Given its role in funding prevention of chronic disease, health services, and research, this department created an initiative with four major goals:\textsuperscript{30}

1. Foster health care and public health system changes to improve the health of individuals with multiple chronic conditions
2. Maximize the use of proven self-care management and other services by individuals with multiple chronic conditions
3. Provide better tools and information to health care, public health, and social services workers who deliver care to individuals with multiple chronic conditions
4. Facilitate research to fill knowledge gaps about, and interventions and systems to benefit, individuals with multiple chronic conditions

This department acknowledges the complexity in improving health of persons with multiple chronic conditions and the challenge that this group might be heterogeneous. The Patient Protection and Affordable Care Act to reform health care in the United States is encouraging “health homes” for persons with multiple chronic conditions enrolled in Medicaid. As a result of this initiative, the Centers for Medicare and Medicaid Services provide data on chronic conditions among beneficiaries.\textsuperscript{31} For example, state reports on the prevalence of the 15 most common chronic conditions are available for the years 2007-2011 with comparison to national estimates. The second report presents the prevalence, utilization and Medicare spending for Medicare beneficiaries with multiple chronic conditions and allows for the comparison of a specific state to national estimates. Figures of national data are in a separate chartbook. Finally, the chronic conditions dashboard allows users to query state data on prevalence and spending and map it. \textit{Preventing Chronic Diseases} provides previously-published articles on this topic under their collections.\textsuperscript{32}

Follow a Systematic Approach to Program Integration

To assure successful integration efforts, epidemiologists can follow basic guiding principles:\textsuperscript{33}


• Do no harm to categorical program integration.
• Clearly identify and state mutual benefits and opportunities.
• Be guided by efficiency-oriented processes.
• Focus on health outcomes.
• Evaluate integration outputs and health outcomes.
• Engage stakeholders.
• Mobilize leaders.

Authorities also recommend specific state health agency actions to support integration of chronic disease programs:\(^3^4\)

• Engage the agency leadership.
• Develop crosscutting epidemiology and surveillance programs.
• Leverage the use of information technology.
• Build state and local partnerships.
• Develop integrated state plans.
• Engage management and administration.
• Implement integrated interventions.
• Evaluate integration initiatives.

**Utilize System Dynamics**

System dynamics is an approach used to understand relationships and causal mechanisms within complex systems, such as the social systems in which chronic diseases develop. System dynamics considers feedback (causal) loops and time delays, and demonstrates the nonlinearity of system events. A chronic disease system dynamics model or map illustrates, in detailed graphic form, the complex relationships among risk factors, intermediate outcomes, and disease outcomes. Figure 3-1 depicts a system dynamics model for cardiovascular disease, showing the major health conditions related to cardiovascular disease and their causes. Boxes identify risk factor prevalences modeled as dynamic stocks. In Figure 3-1, the three boxes identify the risk factors for first time cardiovascular events and deaths and their associated costs: obesity, smoking and the chronic disorders of high cholesterol, high blood pressure, and diabetes. The population flows associated with these stocks—including people entering the adult population, entering the next age category, immigrating into the system, dying, etc—are not shown.

In the context of chronic disease collaboration, system dynamics models can highlight potential areas for collaboration by demonstrating how diverse risk factors, such as smoking and obesity in Figure 3-1, link to adverse health outcomes, such as cardiovascular disease in Figure 3-1. Thus, both smoking prevention and cessation and obesity prevention can be considered part of

cardiovascular disease prevention. At least two other systems dynamics models have been published: one for tobacco and one for obesity. 35,36


Key:
- **Blue solid arrows:** Causal linkages affecting risk factors and cardiovascular events and deaths.
- **Brown dashed arrows:** Influences on costs.
- **Purple italics:** Factors amenable to direct intervention.
- **Black italics:** Other specified trends.
- **Black non-italics:** All other variables (affected by italicized variables and by each other).

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Leveraging Funding and Strategies to Prevent and Control Chronic Diseases

To optimize public health’s efficiency and effectiveness, the Centers for Disease Control and Prevention (CDC) recommends coordinating chronic disease prevention efforts in four key domains: 38

1. Epidemiology, surveillance, and evaluation to inform, prioritize, and monitor diseases and risk factors and the delivery of interventions.
2. Environmental approaches that reinforce healthful behaviors and expand access to healthy choices.
3. Health systems interventions that improve the delivery and use of clinical and other preventive services.
4. Clinical and community linkages to better support chronic disease self-management.

This approach addresses multiple behaviors, environments, and chronic conditions at the same time, because many of the risk factors for obesity, diabetes, heart disease, and stroke are related and the proven interventions are similar. So integration is not only an idea that makes sense, this CDC example demonstrates that funders might require it.

Resources

Background Reading


Program Integration Checklist by the National Association of Chronic Disease Directors

• The National Association of Chronic Disease Directors has developed a checklist of tasks to help health agency leaders establish and maintain a program integration initiative. Although not comprehensive, it can be adapted for use with a wide range of integration efforts. Available at:  

Community of Learning

• The National Association of Chronic Disease Directors supports a coordinated chronic disease learning community to "assist integration, collaboration, and coordination in addressing chronic disease prevention and control." It is accessible at:  
http://www.chronicdisease.org/?CCD

Case Studies

ASTHO has developed ten case studies highlighting how state chronic disease and maternal and child health programs are working together to deliver chronic disease prevention programs to maternal and child populations using either preconception health or life course health perspectives as the theoretical underpinnings. The 10 case studies listed below are accessible at:  
http://www.astho.org/Collaboration_Between_MCH_and_Chronic_Disease/

• Seizing a “Golden Opportunity” to Improve Birth Outcomes in Louisiana  
Case study of Louisiana’s Birth Outcomes Initiative to engage stakeholders in a process aimed at improving outcomes for women and children.

• Collaborating to Change Arkansas' Health Trajectory  
Case study on the Arkansas Department of Health engaging public and private stakeholders to change the health trajectory for Arkansans.

• Colorado's Collaborative Strategies to Improve Health of Women and Children  
Case study on Colorado's strategies to address the causes for low birth weight babies.

• Partnering to Improve Health Outcomes throughout the Lifespan in Delaware  
Case study on Delaware's Healthy Women, Healthy Babies program, aimed to reduce infant mortality and morbidity across the lifespan.

• Missouri Partners to Reduce Chronic Disease Risk Factors for Women and Children  
Case study on coordinated approach that the Missouri Department of Health took to reverse troubling public health trends with a focus on youth, pregnant women, and systems change.

39 Maternal and Child Health: Collaboration between MCH and Chronic Disease. ASTHO|Association of State and Territorial Health Officials Website. Available at:  
http://www.astho.org/Collaboration_Between_MCH_and_Chronic_Disease/  
• **Building on Partnerships to Achieve Goals in Massachusetts**  
  Case study on Massachusetts partnerships to reduce the prevalence of gestational diabetes and to improve health outcomes for women of reproductive age.

• **Using Data to Drive Diabetes Prevention Efforts in Ohio**  
  Case study on the collaboration of programs and data in Ohio to achieve better results.

• **Turning Public Health Challenges into Opportunities for Collaboration in Utah**  
  Case study on Utah's collaboration to improve data on gestational diabetes.

• **Promoting Healthy School-Aged Children in Vermont**  
  Case study on Vermont's Department of Health's partnership with Medicaid, the Department of Education, the local pediatric community, and local school districts to build capacity among the state's school health nurses and dental health professionals.

• **Building on Seeds of Change in West Virginia**  
  Case study on West Virginia's network of partners that worked towards promoting provider awareness about gestational diabetes testing and follow-up care and improving patients' awareness of gestational diabetes as a major risk factor for Type 2 diabetes.

**Summary**

This chapter provides concrete, common activities across programs, a system dynamic model to broaden your view, and an integration checklist. Ask your colleagues to provide examples of collaboration and integration. Ask if any of the following would be helpful:

- **Surveillance:** Identify common target groups, settings, and risk or protective factors across populations with different chronic diseases. Identify subpopulations with multiple chronic conditions.

- **Communication:** Use the list of common activities in the “Recognize Opportunities for Program Integration section, the examples from other states and the program integration checklist by the National Association of Chronic Disease Directors to start the conversation with other programs about existing integrated activities and opportunities.

- **Consultation:** Ask other programs if any of the common activities is a priority. Identify mutually beneficial ways to collaborate.

The next two chapters—Chapter 4: System Approaches and the Social Ecological Model and Chapter 5: Evidence-based Public Health—review concepts that will assist you in thinking about integration and in taking steps to promote effective, collective public health approaches.
Chapter 4: System Approaches and the Social Ecological Model

Upstream Possibilities—A Public Health Parable

A man and woman were fishing downstream and suddenly a person came down the river struggling for life. The fisher folk wade into the quickly moving water and pull the person out, saving her life. Then another person comes along and again must be rescued. This happens all afternoon and the fisher folk get very tired from constantly pulling people from the river. Eventually they think, “We need to go upstream and find out why so many people are falling in the water.”

When they go upstream, they find that people are drawn to the edge to look at the river, but there is no safe way to do this and many of the people keep falling in. The fisher folk go to the community leaders and report the number of people who have fallen into the river. They also report that this is because of the lack of a protective barrier on the cliff. Community leaders build a wall behind which people may safely view the water. Some still fall, but there are many fewer people to rescue.

—Author unknown

In addition to measuring chronic disease burden, chronic disease epidemiologists have the opportunity to look upstream and work with program partners to implement prevention and control strategies with potential to impact the greatest number of residents. Therefore, this chapter reminds you as the lead chronic disease epidemiologist that different levels of society can impact individual behavior and that several frameworks describe these levels or interventions at these levels. This chapter will foster your thinking about how social context and community factors can drive behaviors affecting chronic diseases. Part of your role as the lead chronic disease epidemiologist is to measure these contextual factors to better understand the relationships among the environment, individual behaviors, and population health outcomes. Additionally, this chapter describes the potential role of these relationships in informing the development of policy, systems, and environmental changes targeted at the different societal levels to help promote improved population health. While individuals are responsible for initiating and maintaining the behaviors necessary to reduce risk and improve health, their behavior is influenced to a large
extent by the context in which they live (i.e., social determinants of health). The social forces are life threatening. Researchers from Columbia University estimated deaths attributable to social factors in the United States in 2000: 245,000 deaths attributed to low education; 176,000 to racial segregation; 162,000 to low social support; 133,000 to individual-level poverty, 119,000 to income inequity, and 39,000 deaths to area-level poverty.\(^4^0\) As stated in a 2000 Institute of Medicine report on health promotion, "It is unreasonable to expect that people will change their behavior easily when so many forces in the social, cultural, and physical environment conspire against such change."\(^4^1\) By identifying determinants of health, you as the lead chronic disease epidemiologist can guide interventions that help communities overcome these barriers and allow for the healthy choice to become the easy and life-extending choice.

For the senior epidemiologist or professional who supervises or mentors the lead epidemiologist, you can use this chapter to identify and share previous analyses that informed environmental, system, or policy changes and their success or failure in preventing chronic diseases or reducing the impact of diseases on activities of daily living. If your department has its own model for systems thinking and/or for social determinants of health, provide it to the lead chronic disease epidemiologist. For the entry-level epidemiologist assess whether or not the surveillance system that you use or know best includes measures of social or environmental context.

Understand the Levels of Public Health Intervention and Their Influence

Public health interventions to prevent and control chronic illness can be implemented at any (or all) societal level(s), from the individual to the institutional to the entire community or state. More recently state public health departments have shifted from providing or funding individual direct services (intervening directly at the individual level) to improving a system of services (intervening at the organizational and community level).

**Social Ecological Model**

A useful framework describing a systems approach at various societal levels is the Social Ecological Model (Figure 4-1).\(^4^2\) This model recognizes and articulates the relationship between the individual and their environment. The Social Ecological Model can have four or five levels. At the center or base is the **individual** level of internal determinants of behavior, such as knowledge, attitudes, beliefs, and skills. The **interpersonal** level comprises the external influences of family and friends, social norms, social identity and role definition form and operate at this level and can influence lifestyle and health care choices. The

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institutional or organizational level considers the rules and policies that guide and support behavior, including healthy behavior, in the assemblies that aggregate interpersonal associations, such as the workplace, schools and social organizations. The fourth level, the community, is the collective network of individuals, businesses, institutions and organizations. These larger social constructs, which include the media and advocacy groups, can be defined by geography, membership, heritage or affiliation. The last level, the policy level, describes the authoritative decisions made by a local, state, or federal governing body that can influence all the other levels. For example, federal, state, local or tribal government officials can support chronic disease prevention and control through laws, ordinances, regulations or proclamations.

Figure 4-1. Social Ecological Model
The Health Impact Pyramid

Dr. Thomas Frieden's five-tier, Health Impact Pyramid, Figure 4-2, can be described as an adaptation of the Social Ecological Model. In place of the five levels of possible public health intervention, the pyramid depicts five types of interventions and their relative population reach. The five tiers of the pyramid are, from bottom to top, socioeconomic factors (e.g., decreasing the negative impacts of poverty), changing the context to make individuals’ default decisions healthy (e.g., eliminating trans fat), long-lasting protective interventions (e.g., colonoscopy, treatment of tobacco addiction), clinical interventions (treatment of hypertension and hyperlipidemia), and counseling and education (e.g., dietary counseling). Like the Social Ecological Model, the Health Impact Pyramid suggests that interventions with greater population reach—and which require least individual effort—will have the greatest overall public health impact. Moreover, these population-level interventions are potentially more sustainable as, unlike individual-level focused activities, they typically do not require considerable ongoing financial support and are not impacted by limits in scalability.

Figure 4-2. The Health Impact Pyramid
Figure used with permission from AJPH. Frieden TR. A Framework for Public Health Action: The Health Impact Pyramid. *Amer J Pub Health*. 2010; 100(4): 590–595.

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The Maternal and Child Health Pyramid

The “MCH pyramid” is a conceptual framework for four tiers of services funded by the Title V Maternal and Child Health Block Grant (http://www.amchp.org/AboutTitleV/Documents/MCH_Pyramid_Purple.pdf). Older than the Health Impact Pyramid, this framework used a pyramid to show the same impact, that the lowest tier had the largest reach in terms of population impact and the top tier the smallest. Its four tiers from top to bottom are:

- Direct health care services (for gap filling)
- Enabling services (transportation, translation, outreach, respite care, health education, family support services, case management coordination with Medicaid)
- Population-based services (newborn screening, lead screening, immunizations, oral health, injury prevention, nutrition, outreach, public education)
- Infrastructure-building services (needs assessment, evaluation, planning, policy development, quality assurance, standards development, monitoring, applied research, systems of care, information systems, training)

Changing the Context in Communities

Additional emphasis on implementing population-level, upstream efforts—and especially on changing the context to make individuals’ default decisions healthy—may be the most promising strategy to maximize the impact of limited resources. One example is the highly successful campaign to reduce the number of public spaces where smoking is permitted; this effort has changed the environment for many smokers and also helped to shift social norms. However, such interventions can be controversial, especially when there are vested interests opposed to changing existing societal norms.

As with public smoking, changing the context can mean changing policies, systems, the environment or some combination thereof. Policy changes occur at the governmental or organizational level and include laws, ordinances, resolutions, mandates, regulations, or rules supporting healthy lifestyle choices; for example, a corporate policy to provide paid time off during work hours for staff to receive health screenings. Systems changes impact the modus operandi in institutional or community settings, such as schools, hospitals, transportation systems and recreational systems; for example, introducing electronic health records within a health care

system to facilitate information-sharing, care coordination and patient empowerment. Finally, environmental changes involve substantive changes to the economic, social, or physical environment; for example, incorporating sidewalks, and recreation areas into community design.

Some prominent "context-changing" interventions include:

- Fluoridation of drinking water, a cost-effective measure that is helping to prevent tooth decay among the estimated 210.7 million U.S. residents serviced by fluoridated public water systems.\(^{47,48}\)
- Iodization of salt to prevent iodine deficiency and associated disorders, including goiter, hypothyroidism, and congenital hypothyroidism.\(^ {49}\)
- Eliminating artificial trans fat from foods and moving from use of saturated to unsaturated cooking oils in restaurants to improve cardiovascular health.\(^ {50}\)
- Introducing healthy vending machine foods in schools and worksites to reduce obesity and improve nutrition.\(^ {51,52}\)
- Mandating, at the school system- or state-level, that elementary school students receive at least the recommended 30 minutes of daily physical activity during each school day to reduce obesity and enhance cardiovascular health and fitness.\(^ {53}\)
- Instituting Complete Streets—roadways designed to safely and comfortably provide for the needs of all users, including, but not limited to, motorists, cyclists, pedestrians, transit and school bus riders, people with disabilities, and emergency users—to promote physically active transportation.\(^ {54,55}\)


\(^{52}\) Lawrence S, Boyle M, Crayp L, Samuels S. The food and beverage vending environment in health care facilities participating in the healthy eating, active communities program. \textit{Pediatrics} 2009;123:5287-5292.


Develop a Coordinated Response

As noted in Chapter 2, as the lead chronic disease epidemiologist, build relationships with a broad range of partners within and outside the state public health department to achieve population-level improvements in health. In addition to established professional and voluntary associations interested in chronic disease issues, virtually all states have several statewide coalitions working to reduce the burden of specific diseases or risk factors. Other potential chronic disease stakeholders include hospitals, health insurance groups, health care quality improvement organizations, schools, faith-based institutions, employers, community members and others (Figure 4-3). Although these stakeholders have traditionally worked independently (or in limited partnerships) to address specific interests, there is increasing awareness of the value of coordinating activities to achieve common goals and attempts to collaborate to do so.

![Figure 4-3. Stakeholders involved in the implementation of chronic disease prevention and control interventions.](image)

One strategy that has been implemented to increase coordination across sectors is the development of comprehensive state chronic disease control plans. Some state chronic disease programs have used Coordinated Chronic Disease Grant and other funding from the CDC to create these with input from various partners. While programmatic initiatives should comprise a key component of a state plan, a major focus for many plans will be interventions to "change the community context" via policy, systems and environmental changes. The state plan should:

- Identify well-defined, measurable goals and, perhaps, an overall vision statement.
- Identify key process and health outcome indicators that can be tracked over time at the state level and, when possible, at the local level to evaluate and refine interventions to achieve goals.
- Document each stakeholder's role in carrying out portions of the plan.
- Identify mechanisms to report progress and other feedback to plan stakeholders.
If the plan includes all of the above, it mirrors the five principles of collective impact: a shared agenda, mutually reinforcing activities, measurable performance objectives, regular communication, and a backbone organization.

Ultimately, these state plans should be adaptable to individual communities’ unique contexts and concerns. Chronic disease epidemiologists should encourage communities to conduct or update their own community assessments, using primary and secondary data to assess current social conditions. Such assessments are vital to illuminate the “conditions on the ground,” including readiness for change, so that appropriate interventions that support the overall state plan, but are specific to the local community, can be selected, implemented, and evaluated. The CDC Healthy Communities Program’s Community Health Assessment and Group Evaluation (CHANGE) tool is designed to facilitate this assessment process: "It can be used annually to assess current policy, systems, and environmental change strategies and offer new priorities for future efforts." The tool is available at www.cdc.gov/healthycommunitiesprogram/tools/change.htm. Overall, the promise of a coordinated, statewide effort is a synergistic effect, with the total impact being greater than the sum of each stakeholder's individual efforts.

Other assessments can inform these plans. Every five years the federal Maternal and Child Health Bureau as part of the Title V block grant require states to conduct a state needs assessment that includes state and local input and to use this assessment to select priorities for the next five years. Many states as either part of the public health accreditation process or as part of their public health improvement process require a needs assessment that can include a public health capacity assessment and priority setting.

However, no matter what community assessment tool is used or what interventions are prioritized and implemented, the following are needed to support positive changes at both the state and local levels:

- Effective public-private partnerships.
- Targeted policy and environmental changes embedded in broader community initiatives.
- Continued engagement and interaction with the broader community.
- A meaningful, long-term commitment from partners work towards desired outcomes.

State and local groups need to place greater emphasis on population-level, upstream efforts to successfully decrease the growing burden of chronic disease and associated risk factors. Many of these efforts should attempt to change the community context through policy, systems, and environmental changes. State health departments’ chronic disease programs and their partners should consider working toward consolidating each of the targeted chronic disease state plans into one overarching plan, highlighting the important role each disease-specific group can play to achieve desired health outcomes. With this collaborative framework in place, stakeholders

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throughout the state can move upstream and impact population health in the most effective and efficient way possible.

Resources and implementation examples
The list of articles and web sites below provide examples of system approaches, such as the social ecological model, and evaluating community change related to various chronic disease risk factors and outcomes. Included are articles and web sites related to social determinants of health which take a system approach to address specific risk factors or outcomes. These resources are provided as a reference for you as the lead chronic disease epidemiologist. Select which ones to read in detail, based on the current need and priorities in your state.

Articles

- [http://www.publichealthreports.org/](http://www.publichealthreports.org/)

Implementing SEM concepts in an analysis: example
Singh, Siahpush, and Kogan (2010) examined the relationship of neighborhood socioeconomic conditions and obesity and overweight prevalence among U.S. children and adolescents using the 2007 National Survey of Children's Health. The odds of a child's being obese or overweight were 20-60 percent higher among children in neighborhoods with the most unfavorable conditions such as unsafe surroundings; poor housing; and no access to sidewalks, parks, and recreation centers, compared to children living in better conditions.
Web sites

CDC Colorectal Cancer Control Program— [http://www.cdc.gov/cancer/crccp/sem.htm](http://www.cdc.gov/cancer/crccp/sem.htm)
CDC Social Determinants of Health— [http://www.cdc.gov/socialdeterminants/](http://www.cdc.gov/socialdeterminants/)

Summary

The information in this chapter can inform your competency in the domain of community dimensions of practice\(^{57}\) in a way that also increases the potential impact of the interventions. It can enhance your competency in systems thinking,\(^{58}\) which in turn might give you opportunities to demonstrate leadership as you think across the community levels and partnerships. The main points related to the three public health essential services that epidemiologists provide are:

- **Surveillance:** Your role is to coordinate and conduct chronic disease surveillance, including helping to establish new standard indicators related to risk and protective factors at the individual and system level. You can influence what contextual factors and social determinants of health are measured and analyzed. Only then can you bring this vital information to the policy discussion and to program planning. You can assess the impact of the new policies or interventions.
- **Communication:** Your role is to communicate scientific and technical information in a way that decision makers can use it. Select one of the frameworks as a way to communicate varying impact of possible interventions on population health. Building a collaborative, integrated state chronic disease plan demands good listening skills and the ability to translate information using language and concepts from multiple disciplines and clinical fields.

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• Consultation: Through your consultation, you connect the science and data to the policy options and policy makers in your state. You have the opportunity to work with family leaders, advocates, stakeholders, organizations and communities representing different social ecological levels and understandings of public health need and impact. You can connect state activities with state health assessments and advocate for evaluating the interventions that are not evidence based or monitor the fidelity to the evidence-based program. Read the next chapter for more about evidence-based public health and your role in it.
Chapter 5: Evidence-Based Public Health

The term *evidence-based public health* entered the professional lingo in the late 1990s. In brief, an evidence-based public health approach combines the best available research, practitioner expertise, and community preferences to inform all the stages of program planning, implementation, and evaluation to improve population health. As a *lead chronic disease epidemiologist*, using an evidence-based approach provides you a collaborative yet systematic process for identifying opportunities for integration that leads to data-driven, effective strategies for implementation. This approach builds the collaborative team, the common understanding of effective strategies, a common agenda, mutual reinforcing activities, and shared performance measures (or a full evaluation plan). In other words, you can use this approach for collective impact, if you add continuous communication, and “backbone support.” ⁵⁹ For the *senior epidemiologist* or professional who supervises or mentors the lead epidemiologist, begin thinking about what issue or problems in your state could benefit from this approach. Or identify which existing chronic disease prevention activity needs evaluation. For the *entry-level epidemiologist*, ask to help with a literature review or read the literature supporting strategies that CDC recommends for chronic disease prevention and control.

Public health departments increasingly need to justify public health activities to funders. Indeed, both the American Recovery and Reinvestment Act of 2009⁶⁰ and the Patient Protection and Affordable Care Act of 2010⁶¹ emphasized evidence-based prevention strategies. As more federal grants require evidence-based programs, evidence-based public health is becoming a default expectation at all levels of government, because while an evidence-based public health approach makes public health practice more rigorous, it also makes public health more effective. Though evidence can be limited on specific interventions for chronic disease prevention and control, reviewing what, if any evidence, is available provides information for making the best-informed decision as possible, including deciding to find funding to evaluate a promising intervention that does not have a strong evidence base.

An evidence-driven approach to public health practice depends upon (1) availability of scientific evidence to support specific interventions or policies, (2) translation of the science-base for community-focused public health practice, (3) a well-defined process to apply the evidence to decision-making, and (4) mechanisms to share the science base for chosen interventions at the state and local levels.

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Although different approaches to evidence-based practice exist, there are several common components:\(^\text{62}\)

- Use of the best available scientific evidence to inform decision-making
- Systematic use of data and information systems
- Use of program-planning constructs
- Community engagement in assessment and decision-making
- Evaluation at every stage of the process
- Dissemination of findings to stakeholders and program implementers

The underlying skills needed to execute these components are not new. A popular construct for applying these skills is Ross Brownson’s seven-step framework (Figure 5-1). Though sometimes depicted otherwise, this process is nonlinear and may require multiple iterations before the team develops a refined strategy for public health practice.

Whether ensuring that program activity is properly informed or delivering technical assistance to stakeholders, you as the lead chronic disease epidemiologist might have the challenge of insuring that public health activity is grounded in scientific evidence. Before embarking on your own evidence review, look for existing reviews. Organizations, like the Institute of Medicine\(^\text{63}\) and the CDC,\(^\text{64,65}\) have recommended public health interventions for various chronic diseases and risk factors, based upon expert reviews of the evidence at the time that they were created. If the review is not recent, then you can consider repeating the review with only the more recently published literature. Training a team in evidence-based public health combined with the systems thinking frameworks from the previous chapter is one way for developing capacity to address the challenge of providing effective public health practice in chronic disease prevention. Mutual understanding

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among epidemiologists, program colleagues and external partners can result as each of you gains greater insight on how your respective expertise contributes to improving population health.

Resources
These resources are provided for your future reference, if needed, based on your assessment of your knowledge and skills and on the priorities for your position in the short term and long term.

Background Reading

The last three articles are available from the ASTHO website at: www.astho.org/Programs/Evidence-Based-Public-Health/Articles-on-Evidence-Based-Public-Health/?terms=evidence-based+public+health

Online Tutorials and Tools
- University of Washington Health Sciences Library: http://libguides.hsl.washington.edu/ebptools
- University of Massachusetts Medical School Library: http://library.umassmed.edu/ebpph/
- Supercourse: http://www.pitt.edu/~super1/lecture/lec18061/index.htm
- University of Michigan School of Public Health: http://www.sph.umich.edu/mi-info/10-ebph/index.html

Organizations Advancing Evidence-Based Public Health
The American Heart Association: [http://my.americanheart.org/professional/StatementsGuidelines/ByTopic/TopicsD-H/Hypertension_UCM_321621_Article.jsp](http://my.americanheart.org/professional/StatementsGuidelines/ByTopic/TopicsD-H/Hypertension_UCM_321621_Article.jsp)

The Campbell Collaboration: [http://www.campbellcollaboration.org](http://www.campbellcollaboration.org)

The Cochrane Collaboration: [http://www.cochrane.org](http://www.cochrane.org)


The Prevention Research Center: [http://prcstl.wustl.edu/EBPH/Pages/default.aspx](http://prcstl.wustl.edu/EBPH/Pages/default.aspx)

Since 1997, the Prevention Research Center in St. Louis has offered an evidence-based public health training course to promote the practical application of these concepts. This course is available to chronic disease health officials directly and through a competitive, state-based train-the-trainer program. State health officials who have received this training then train their respective local health departments, health coalitions, and community stakeholders.

Public Health Foundation: [http://www.phf.org/programs/communityguide/Pages/default.aspx](http://www.phf.org/programs/communityguide/Pages/default.aspx)


Summary

This chapter covered an evidence-based public health approach as a collaborative, systematic process for connecting data, science, stakeholders, partners, policy makers, and effective strategies for public health action. The steps of the Brownson model are common in isolation. However, you as the lead chronic disease epidemiologist have the opportunity to connect these steps in a way that furthers chronic disease integration.

- Surveillance: Your analysis and interpretation of the chronic disease surveillance data, especially risk and protective factors related to health outcomes, is necessary to quantify the issue, a key step in evidence-based public health and in focusing the review of the scientific literature (a subsequent step in evidence-based public health).

- Communication: Your ability to summarize, interpret, and communicate information from each step in an evidence based public health approach makes the next step more focused and relevant to the overall goal. You ensure that relevant, understandable information inform decisions about what public health action is warranted and appropriate.

- Consultation: Your consultation on each step of evidence-based public health truly connects the science and data to the policy options and policy makers in your state. Your competency in searching, reading, synthesizing and interpreting scientific research, regardless of the topic, ensures that effective strategies are options for public health programming and implementation. Using your talents to guide your program and department in planning and implementing
evidence-based strategies for chronic disease prevention and thereby meeting a CSTE recommendation is immensely satisfying.66

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Chapter 6: Data Governance

As emphasized throughout this orientation manual, two major points of focus for you as the lead chronic disease epidemiologist are data and partnerships—the vital means for achieving efficient and effective chronic disease surveillance and program evaluation to undergird efforts to improve population health. Data—especially personally identifiable data—is subject to a number of legal strictures governing its collection, availability and usage, referred to as “data governance”. To navigate this state and federal terrain, you as the lead chronic disease epidemiologist must be familiar with state statutes and public health reportable conditions, data user agreements, institutional review boards (IRB), and the like. These data governance topics are the subject of this chapter. The aspect of data governance not covered in this chapter is the decision making about what data to collect for what purpose. To address this gap and to bring this chapter alive, ask to observe an IRB meeting and a Board of Health meeting where the board is considering a new reportable condition or change in an existing reportable condition.

For the senior epidemiologist or professional who supervises or mentors the lead epidemiologist, you can use this chapter to highlight which topics are most relevant to your department or state, to illuminate nuanced differences, to share additional topics not covered, and decide how best for the lead epidemiologist to learn about the Board of Health and its rulemaking, especially related to reportable conditions. (For example, in Colorado, cancer is required to be reported by hospitals, diagnostic and/or treatment clinics, and pathology laboratories.) Show the lead epidemiologist where to access state statutes and Board of Health rules related to any and all chronic diseases, the cancer registry, and/or disability. Ensure that the lead epidemiologist knows the chain of command and approval process related to contact with a state legislator or with the governor’s office. For the entry-level epidemiologist assess whether or not the surveillance system that you use or know best covers all aspects of the framework for public health surveillance. Read the documentation that forms the basis of the authority to conduct the surveillance system, whether it is a Board of Health rule or an IRB-determined ruling that this surveillance is deemed public health practice.

As a simple reminder of the comprehensive data collected in chronic disease surveillance and the public health actions that data inform, the following framework is presented. The legal requirement to protect privacy, the detailed and personal nature of these data and the potential for harmful use drives the protections and security that governs them. It is these very protections, how they are determined, and how they can be changed that you as the lead chronic disease epidemiologist must understand.
Surveillance is one of three critical functions of a lead chronic disease epidemiologist. You as the lead chronic disease epidemiologist must provide critical leadership to assure adequate capacity to survey chronic diseases and associated risk factors and to assure the relevance, quality and appropriateness of the collection, analysis, and interpretation of the data. Advances in information technology have created expectations for surveillance that is real-time, accurate, and automated.

Brookmeyer and Stroup define public health surveillance broadly to include “all types of data collected from populations that could be useful in guiding public health activities.” They propose a framework (Figure 6-1) depicting the relationship among a variety of data types, levels of intervention and prevention opportunities. Inclusion of “social determinants” in this framework—encompassing everything from health care access to community safety—is a poignant reminder of the broad context of chronic disease epidemiology and the need to forge a variety of partnerships to assure access to data and to populations to carry out core public health activities.

As mentioned in Chapter 2, surveillance is a vital function of a lead chronic disease epidemiologist, such that CSTE ranked it as one of the top three functions for this position. Though evaluation of health services was deemed a supportive function of a lead chronic disease epidemiologist, evaluation—like surveillance—requires data. Therefore, it is useful to repeat the evaluation role of a lead chronic disease epidemiologist to:

- Further the design and implementation of scientifically sound evaluations of the outcomes of health services and health promotion/disease prevention programs, assessing effectiveness, accessibility, and quality.
- Assist program managers and decision-makers in using evaluation results to enhance effectiveness of existing programs and to design new programs addressing identified needs.
- Perform evaluation activities, such as analysis and interpretation of data to discern program impacts using both qualitative and quantitative methods.

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69 CSTE. *Essential Functions of Chronic Disease Epidemiology in State Health Departments*. 2004.
In addition to performing these essential functions, you as the lead chronic disease epidemiologist will assist in building and evaluating long-term surveillance capacity, by assuring access to data and data consultants, maintaining capabilities for data analysis/interpretation, and maintaining partnerships with a long list of chronic disease stakeholders from community leaders to academicians.

Know the Statutory Authority to Conduct Public Health Action

Federal and state laws govern public health practice in the United States, including public health surveillance. They describe in broad terms the powers and duties of a public health entity and also its limitations. Key is the balance between the Constitutional rights of individuals and the public health needs of the community as well as the relationship of the federal government to state government (federalism) in the U.S. Constitution. The sources of law necessary for public health practice include: constitutions, statutes by legislatures, administrative law by executive branches of government, and common law (including case law) by judicial court systems. As the lead chronic disease epidemiologist, you will need to know about relevant state statutes and state administrative laws (disease reporting regulations, for example).

State constitution and state statutes: Because the U.S. Constitution does not mention “public health”, the primary responsibility for public health was left to states. States have their own state constitution as sources of legal authority. State laws must meet U.S. Constitutional protections (due to the 14th Amendment). The state’s own constitution provides for the establishment of state and local government branches and powers. It is your state statute that gives power to executive branch agencies, such as state public health departments. As the new lead chronic disease epidemiologist, read the portions of the state statutes that apply to public health, the Board of Health, and chronic diseases. Look for how it defines public health duties and chronic diseases, including the public health use of data. Understand how it protects confidential data when your public health department gathers, accesses, stores, and uses them. Usually, it limits data access to public health professionals involved in the disease control efforts (though for communicable diseases often persons at risk can be notified), and the data cannot be released to prosecutors and tort lawyers. In addition to the protections in state statute, there is the federal privacy law, the Health Insurance Portability & Accountability Act (HIPAA), which is discussed later in this chapter. Federal regulation regarding research and human subjects protection is also discussed later. Finally, related to state statute, ask if there are public health exceptions in your state’s open records act.

Regulation: Legislatures through state statute can give state agencies the power to make administrative regulations that have the same force as statutes. Examples include the state board of health designating notifiable diseases or reportable conditions or setting enforceable environmental measures. Promulgating and amending regulation can be quicker than passing statutes, allowing states to address new challenges quickly. So as the statute describes and limits the general authority for public health, the regulation can address highly technical details in how that authority is carried out. For example, many state public health departments designate
reportable diseases and specify the manner of reporting in an administrative rule by the Board of Health, rather than in a statute. This administrative rule power gives the department the flexibility to add diseases or change reporting standards without new legislation. The administrative rule gives clear guidance to the persons with a duty to report. Both federal and state laws require agencies to allow for public participation in this rule making. As the new lead chronic disease epidemiologist, review any Board of Health rules related to chronic diseases and related risk factors, such as tobacco and obesity. Also learn about state laws and local ordinances related to physical activity (such as physical activity requirements in schools), nutrition (menu labeling, for example), or environmental (secondhand smoke exposure). Ask about any excise taxes, such as on tobacco.

Under the U.S. Constitution, U.S. Congress has enacted statutes creating a federal public health infrastructure (for example, the U.S. Public Health Service) and federal agencies with public health powers (CDC, FDA, OSHA, EPA, NHTSA). The federal government can and does influence state public health through its regulatory duties (federal school lunch program, for example) and through its funding (and defunding) of public health, including chronic disease prevention funding and school health funding.

For more information than summarized here, such as due process, police powers, quarantine, the recent legal concept of personal privacy (1977), and emergencies, go to the source for this information: http://www.cdc.gov/phlp/publications/phl_101.html

Cancer is a nationally notifiable condition. States must report cancer cases to CDC annually. 70

Understand the Data Use Agreement

A data use agreement is a common means to gain data access or provide it to others. It can reflect information from federal and state statutes as well as state regulation. This contractual document is used for the transfer of data that is nonpublic or subject to usage restrictions—the type of data often required for research. Standard terms of data use agreements protect confidentiality, while permitting appropriate publication or other sharing of research results in accordance with applicable laws, policies and regulations. Typically, a state health department will have a designated signatory authority. State health departments can use data use agreements within its department to administer a person’s access to data based on their role related to a specific reportable condition. For example, the cancer registry program might have a data use agreement with the internal steward of the hospital discharge data owned by an external hospital trade association.

Sample elements of a data use agreement include:

• Brief description of project(s) and intended use of the data, such as clinical research, health services research, or analyses to address public policy issues.
• Brief description of the subject area(s) to be investigated, such as health outcomes or service utilization.
• Brief description of the potential uses of the final products that may be created using the data, such as reports, quality measurements or performance measures.
• Assurances that the requestor:
  o Will use only the dataset, or any part thereof, as permitted by the agreement.
  o Will prohibit others from using or disclosing the dataset, or any part thereof, except as permitted by the agreement; typically for research and aggregate statistical reporting.
  o Will keep data in a secure environment, with access limited to authorized users.
  o Will not release or disclose, and will prohibit others from releasing or disclosing, any information that identifies persons, directly or indirectly, except in cases explicitly permitted under the agreement.
  o Will comply with the privacy rule of the Health Insurance Portability and Accountable Act of 1996 (HIPAA).
  o Will not release or disclose information where the number of observations in any given cell of tabulated data is less than six.
  o Will not release or disclose information where the total population in any given subgroup of tabulated data is less than 50.
  o Will not release or disclose—and will prohibit others from releasing or disclosing—the dataset, or any part thereof, to any person who is not a member, agent, or contractor of the organization that is a signatory to the agreement.
  o Will require all those who will use or have access to the dataset (e.g., employees, agents or contractors of the signatory organization) to sign a copy of the agreement.
  o Will not attempt, and will prohibit others from attempting, to link the records of persons in the dataset with individually identifiable records from any other source.
  o Will not attempt to use, and will prohibit others from using, the dataset to learn the identity of any person included in the data set.
  o Will not contact or permit others to contact facilities or persons in the datasets.
  o Will not sell, market, or transfer the data, or cause or allow the transfer of the dataset or any part thereof.

Determine Whether Your Project is Research, Surveillance, or Evaluation
Research, surveillance, and evaluation share similar designs, data collection methodologies, analytical methods, and quality measures (e.g., statistical validity). However, there are also important differences among the three in terms of their purpose and guiding questions; their intended audience; and the means employed to interpret, report and use findings.
Lee, Teutsch and other authors of the text, *Principles & Practices of Public Health Surveillance* note several specific purposes of surveillance:  
- Helping to assure accurate diagnosis and treatment.
- Enabling appropriate public health management of persons exposed to disease.
- Identifying disease outbreaks (or epidemics).
- Guiding population-based public health prevention programs.

Generally, surveillance required by federal or state law or by state or local public health mandate is not considered research. Voluntary reporting of risk behaviors, chronic disease knowledge, and chronic disease diagnoses might or might not be considered research. The purpose of research is to identify generalizable knowledge. “Generalizable knowledge means new information that has relevance beyond the population or program from which it was collected.” Research attempts to prove (or disprove) a hypothesis, to inform an audience external to the research organization, to ask “what is” and explain “how it works,” and to use findings to draw conclusions specific to the tested hypothesis that contribute to new, generalizable knowledge. Evaluation, on the other hand, aims to improve public health or public health surveillance, often informs an audience internal to the organization, asks “what has value” and “what is working,” and uses findings for decision-making about the specific program evaluated.

Importantly, research, surveillance, and evaluation each have their own standards and ethics for public health professionals. As the new lead chronic disease epidemiologist, follow your department’s established process to determine if a project or program is research, surveillance, and/or evaluation. However, a tipping point does exist: if any portion of a study or project qualifies as research, the entire enterprise is considered research.

Each governmental jurisdiction will have its own statutes and administrative rules or procedures governing public health surveillance, evaluation, and research. For example, there may be differences across states in age to consent for research or ability to compensate state employees for participation in research. The lead chronic disease epidemiologist will need to learn the applicable policies in his or her state.

**Use Institutional Review Boards (IRBs) When Necessary**

The IRB is a federally mandated committee, established to assure that the rights and welfare of human research subjects or participants are protected. Human subjects/participants, in turn, are defined as living individual(s) about whom a research investigator obtains data through intervention or interaction (including online interaction) with the individual or through identifiable private information. The IRB has the authority to approve, disapprove, or require modifications to proposed or ongoing human subject research.

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IRBs operates under a federal wide assurance with the U.S. Department of Health and Human Services (HHS), assuring federal funders and the public that the research organization and researchers comply with Title 45 of the Code of Federal Regulations, Part 46 (45 CFR 46), and applicable state laws and institutional procedures concerning protection of human subjects in research. Three fundamental ethical principles underlie this code: (1) respect for personal rights of self-determination (including informed consent and surrogate consent/assent, as well as protection of individual autonomy, individuals with reduced autonomy, subjects and privacy/confidentiality), (2) beneficence to maximize subject benefits while minimizing harms (including the need for risk-benefit analysis, sound research design and appropriate researcher qualifications), and (3) justice or equitable distribution of research burden, costs, and benefits (including subject recruitment and selection protocols and inclusion/exclusion criteria).

Types of IRB Review

Depending on the risk level of research protocol and the participant population, an IRB may conduct either an expedited review or full board review.

An expedited review is carried out solely by the IRB chairperson or designee (rather than the full board) and is generally used for one of two purposes:

- To approve minor changes to a previously approved research project during the period for which approval is authorized (one year or less).
- To determine whether proposed research meets minimal risk standards and can therefore be exempted from further review.

Federal code defines minimal risk as “probability of risk or harm . . . no more than an individual subject would experience and/or ordinarily encounter in their daily life.” Exempted research—including activities such as anonymous medical record reviews—typically must involve no more than minimal risk, not involve intentional deception, not involve sensitive topics or populations, and include appropriate consent procedures.

The term expedited review, however, can be misleading; reviews of this type are not conducted faster or with less rigor. Researchers engaged in human subjects research qualifying for expedited review must still complete a full application form and prepare an informed consent statement. Moreover, investigators cannot assume that research poses minimal risk simply because it involves only interview or survey data. Sensitive questions may cause distress that exposes participants to greater than minimal risk. Loss of confidentiality can cause harm to participants, their relatives, and others. And non-invasive research that poses no physical risk, may nonetheless pose financial

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risk, employment risk or risk of criminal or civil liability, stigmatization, loss of insurability, and/or embarrassment. It is important to consider a comprehensive view of risk.

The HHS Office for Human Research Protection has graphic decision-making tools available to determine whether a research activity is likely to qualify for expedited review or waiver of informed consent requirements. (See Resources at end of chapter.) All human subjects research that fails to meet requirements for exemption or expedited review must undergo a full IRB review.

Ongoing reporting to the IRB might include:
- Number of subjects accrued.
- Unanticipated problems or adverse events.
- Withdrawal of subjects.
- Complaints about the research.
- Summary of preliminary findings, recently published relevant research, or other relevant information, especially concerning research-related risks.
- Copy of the current informed consent document.
- Amendments or modifications to the research.

Exempt Research

Some types of research may not require IRB review. An example is research involving publicly available information. Research involving prisoners, fetuses, pregnant women, or newborns cannot be exempt from IRB review. However, the researcher does not make this determination of exempt research. Rather, researchers should check with their department’s guidelines or IRB policies to identify who will make the determination of whether or not a proposed study is exempt. Even when the IRB determines that the research is exempt from IRB involvement, researchers still have ethical responsibilities to protect participants’ rights.75

Understand Your Obligations under the Health Insurance Portability & Accountability Act (HIPAA)

HIPAA addresses three issues pertaining to personal health information: privacy, security, and electronic data exchange. Specifically, the act provides standards and requirements for electronic transmission of health information and a framework for the nationwide protection of client confidentiality and the security of electronic health information systems.76 Because HIPAA regulations are complex, they should be examined in the context of your own department. The state governmental organization with the mission to protect public health might be its own state department in your state or it might exist within the state human services department or the state

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Medicaid department. Ask if your department is designated as solely a public health entity under HIPAA or as a “covered entity” which provide or pay for health care.

Protected Health Information

HIPAA standards for privacy of individually identifiable health information—commonly known as the Privacy Rule—define protected health information individual identifiers (including demographic information) and any personally identifiable information about an individual’s health/condition or payment for health care.\(^7\)

HIPAA regulations require the protection of protected health information, including, but not limited to, protected health information created, stored, or transmitted in/on the following media:

- Verbal discussions (i.e., in person, on the phone, via video chat);
- Paper (i.e., chart, progress note, encounter form, prescription, x-ray order, referral form, explanation of benefits, scratch paper, etc.);
- Computer applications/systems (i.e., electronic health record, laboratory information system, X-ray, etc.); and
- Computer hardware/equipment (PCs, laptops, pagers, fax machines, servers, cell/multifunctional phones, removable media, etc.).

Individuals have the right to receive an accounting of disclosures of their protected health information, including any disclosures made to an inappropriate individual or entity in error and disclosures made to:

- Meet legal requirements.
- Support public health activities.
- Report abuse, neglect, violence.
- Support health oversight activities.
- Report to judicial/administrative bodies regarding official proceedings.
- Support law enforcement.
- Respond to threats to health or safety.
- Support specialized government functions.
- Report about decedents.
- Provide information for worker’s compensation claims.

The use or disclosure of protected health information must be limited to the minimum necessary to accomplish the intended purpose for which the request was made or limited to the information a client has given permission to disclose via a client authorization.

HIPAA defines following data elements as identifying information:

- Any geographic subdivision smaller than a state (except for the initial three digits of a zip code if current Census Bureau data indicate that the geographic unit formed by combining all zip codes with the same three initial digits contains more than 20,000 people).
- Any elements of dates (except year) directly related to an individual; all ages over 80; and all elements of dates, including year, for ages over 89, except that all such ages and elements may be aggregated into a single category for age 90 or older.
- Telephone number.
- Fax number.
- Electronic mail address.
- Social security number.
- Medical record number.
- Health plan beneficiary number.
- Account number.
- Certificate/license number.
- Vehicle identifier and serial number, including license plate number.
- Device identifier and serial number.
- Web universal resource locator (URLS).
- Internet protocol (IP) address number.
- Biometric identifiers, including finger and voice prints.
- Full face photographic images and any comparable images.
- Any unique identifying number, characteristic, or code not assigned by the investigator by which one could identify or could reasonable expect to identify the participant.
Resources


CDC Surveillance Practice: Legal, Ethics, Policy at http://www.cdc.gov/surveillancepractice/policy.html
Includes additional resources on data sharing agreements, ethics, HIPAA privacy rule, human subjections protection, legal and regulatory issues, and meaningful use of interoperable electronic health records.

Federal Policies on Human Subjects Research


Tools and Educational Materials on Human Subjects Research


Federal Privacy Policy


Federal Policy on Research Misconduct

Summary

This chapter provides you with a basic overview of statutes and regulations that govern data access and use.

- Surveillance: State and federal laws govern data access and use, especially state statutes, state Board of Health regulations, federal Health Insurance Portability and Accountability Act (HIPAA) and the federal protection of human subjects in research. Understand the statute and Board of Health regulations that authorize your department to collect and use data on chronic diseases, especially any limits on the type of data and their use. As a lead chronic disease epidemiologist, you might need to know more than one reportable condition or notifiable disease. Compare the characteristics of research and program evaluation to the uses of chronic disease data, especially for the diseases that are not a reportable condition. Ask if historically any of the chronic disease surveillance systems were used in research. In many states, the cancer registry is one of the oldest chronic disease data systems. Ask its manager about its state statutes, any regulation, and any research that used registry data. Ask to see the IRB forms for the research that used cancer registry data, if still available. Ask how the cancer registry is used to improve population health. Ask how they provide aggregated results and/or censor data to protect confidentiality. Learn the topics of all reportable conditions as one way to learn about unique data systems in your department. For example, maternal mortality, though rare, might be reportable and findings from the maternal mortality review might be of interest.

- Communication: Your role is to communicate scientific and technical information in a way that decision makers can use it. Practice and prepare by writing a brief justification for the BRFSS being a public health practice under state statute. Then compare your justification with any actual justification (such as in the funding announcement from CDC or in your state’s application to CDC for funding).

- Consultation: It is often through your consultation that you connect the science and data to the policy options and policy makers in your state. Ask if there are any proposed changes to the chronic disease statutes or related Board of Health regulations. Ask if you will need to provide a scientific justification for the changes. Ask about the process for making changes, identifying constituent support, and selecting persons to testify.

Having reviewed data governance, you are ready to dive into the details of the data sources and indicators used in chronic disease surveillance, oral health, and maternal and child health in Chapter 7.
Chapter 7: Surveillance—Data Sources and Indicators

Chronic disease surveillance—the ongoing data collection, analysis, interpretation, and translation for decision-making is the most important function of a lead chronic disease epidemiologist. Your essential role as the lead chronic disease epidemiologist is to identify, quantify and monitor chronic disease risk factors and disorders; to inform program planning and make the case for public health intervention; and to evaluate program effectiveness and document successes. Without relevant, reliable data, you and your department could not practice evidence-based public health.

As a lead chronic disease epidemiologist, become an expert in several data sources used for chronic disease surveillance and their analyzed results in the form of standard indicators used in chronic disease epidemiology, oral health, and maternal and child health. Ask colleagues and the senior epidemiologist (or your supervisor) which data sources and standard indicators are routinely used for chronic disease surveillance in your state. Familiarize yourself with data sources the department manages, which data sources need to be overhauled and which ones are going through major changes, such as the hospitals implementing ICD-10-CM by October 1, 2014. Ask for examples of an integrated data product from the department that used indicators on chronic diseases, oral health, and maternal and child health together. For the entry-level epidemiologist, learn about one data source unfamiliar to you and one set of standard indicators.

This chapter reviews the uses of surveillance and its scope, describes data sources commonly used for chronic disease epidemiology and state surveillance in terms of the topic and population covered. This chapter highlights existing standard indicator sets for chronic disease, maternal and child health, and oral health surveillance and illustrates them with a few example indicators.

Review the Purpose of Surveillance

Chronic disease surveillance is relatively new compared with infectious or communicable disease surveillance and very needed. Its overall purpose, however, is the same: to monitor risk factor and disease trends to inform the development of prevention and control programs, as detailed in Table 7-1 below.

Table 7-1. Uses for Surveillance

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Understand the Scope of Surveillance Data

The Institute of Medicine recommends chronic disease surveillance on risk factors and how they affect disease progression. Because of the cost of high quality data and limited public health resources, the debate arises about the scope of any data system. One side of the debate sees the need to expand surveillance to collect crosscutting information on the “widest possible range of chronic illnesses.” Underlying this position is a broad view of the monitoring role of public health, emphasizing the need to detect new or emerging issues. Surveillance data can generate hypotheses for academic research that pursues discovering new knowledge. The other side of the debate focuses on routine collection of quality data on conditions with known effective prevention and control strategies. Underlying this position is the emphasis on data driving effective public health action and using surveillance data to measure public health performance (SMART objectives that are specific, measurable, achievable, realistic, and time-phased) to demonstrate accountability to funding agencies. This side acknowledges that many of our chronic disease surveillance systems are based on self reported information.

An example of this challenging debate about the scope of a surveillance system: Information on access to healthy foods, such as fresh fruits and vegetables, could justify partnerships between public health and organizations such as Produce for Better Health. It could potentially validate efforts to increase access to fresh fruits and vegetables. Information linked from multiple data sources could inform specific strategies, such as creating local farmers’ markets or subsidizing the purchase of fresh produce. The ultimate goal would be healthier diets to reduce obesity and help to prevent and control conditions like diabetes and cardiovascular disease. Data to evaluate program effectiveness and long-term outcomes could be drawn from multiple sources, such as the

- Recognize cases or clusters of cases to trigger interventions to prevent transmission or reduce morbidity or mortality, including multi-state clusters.
- Assess the public health impact of health events or determine and measure health trends.
- Demonstrate the need for public health programs and resources.
- Inform resource allocation during public health planning.
- Monitor effectiveness of prevention and control measures.
- Identify high-risk populations or geographic areas to target interventions or guide analytic studies.
- Develop hypotheses for analytic studies on risk factors for disease causation, propagation or progression.

Behavioral Risk Factor Surveillance System and point-of-sale receipts. Does the scientific literature provide strong evidence that solely access to fresh fruits and vegetables improves dietary behaviors in individuals and if a large number of individuals in the population make these improvements that the population prevalence of obesity, diabetes, and cardiovascular disease will decrease or at least stop increasing? To help answer this question, multiple well-designed evaluation studies are needed.

A caution to both sides of the debate: do not collect more data than you can analyze and disseminate effectively. This chapter does not resolve this healthy debate. However, you as the lead chronic disease epidemiologist will face this challenge.

Selecting a Health Problem for Surveillance and Public Health Action
If a disease, injury, or condition affects adversely one of the following criteria, public health professionals create a surveillance system to track it and control it:

- Morbidity as measured by increased incidence and/or prevalence
- Mortality as measured by increased death rate
- Case fatality rate as measured by decreased recovery rates
- Lost productivity and/or decreased functioning and quality of life
- Preventability
- Medical costs
- Premature mortality as measured by years of potential life lost, or
- Socio-economic impact (health disparities or inequitable distribution among subpopulations

As demonstrated at the beginning of this manual, the burden of chronic diseases meets almost all of these criteria. They are leading causes of morbidity, mortality, disability, and decreased quality of life in the United States. Chronic diseases account for 70% of all deaths, and about 75% of health spending in the United States. Additionally, they are responsible for the widest health disparity gap among racial/ethnic groups in the United States. While chronic diseases are prevalent, costly, and potentially debilitating or fatal, they and/or their sequelae are, in part, preventable.

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84 CSTE. Essential Functions of Chronic Disease Epidemiology in State Health Departments. 2004.
Know Data Sources for Chronic Disease Surveillance

“The current perspective is that public health surveillance involves a wide range of different systems under a broad conceptual framework, such as an ‘enterprise’ or ‘portfolio,’ rather than a unified system"⁸⁶ or a single data system. Chronic disease surveillance, therefore, uses standard data indicators from many data sources of health behaviors and/or health outcomes in defined populations. These populations range from mothers who recently gave birth, to children, youth, and adults. Data collection techniques can vary from:

- State mandatory reporting by pathology labs of all new cancer tumors to a central registry in a state health department,
- Telephone interviews of adults identified by a random sample of telephone numbers,
- Dental hygienists providing an in-person, oral health screening of students in select grades from randomly sampled public schools.

Many national data sources, such as the Behavioral Risk Factor Surveillance System, can provide both national and state estimates. Some sources are truly a census of all events of interest; others provide population-based estimates using sampling and weighting methodology.

In their list of major CDC Chronic Disease Surveillance Systems,⁸⁷ CDC includes data sources and indicators that provide state and national estimates:

- The Behavioral Risk Factor Surveillance System of adult-reported behaviors and outcomes
- 124 Chronic Disease Indicators (from multiple sources)⁸⁸
- Chronic Disease State Policy Tracking System of select nutrition, physical activity, and obesity policies in states
- National Youth Tobacco Survey of public school students in grades 6-12
- Pregnancy Risk Assessment Monitoring System of maternal attitudes and experiences before, during, and shortly after pregnancy
- Youth Risk Behavior Surveillance System of students in public high schools

The National Oral Health Surveillance System, which is being expanded from 9 indicators to 34 existing, revised, and new indicators and 3 developmental indicators.⁸⁹ Though not included in

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the list of CDC’s major chronic disease surveillance systems referenced above, this surveillance system is useful to chronic disease epidemiologists at the state and local level, as they pursue collaboration and integration.

CDC provides disease and risk factor statistics from several sources in a variety of formats for the following topics and more: cancer, diabetes, reproductive health, smoking, physical activity, alcohol consumption, tobacco use, and water fluoridation.\(^9\)

Given the variety and volume of data sources that can inform chronic disease prevention and control, the following examples highlight data sources for risk factors and outcomes, disease registries, and health care that states commonly use.

<table>
<thead>
<tr>
<th>Data Source</th>
<th>Examples of Interest</th>
<th>Population</th>
<th>Overview</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth Certificates</td>
<td>Mother’s weight pre-pregnancy and at delivery, diabetes, hypertension, tobacco use</td>
<td>Newborns with information about the mother and father</td>
<td>State and national vital records departments collect a census of live births using a standard form, including mother’s information. The standard birth certificate was revised in 2003, though states implemented it in different years. <a href="http://www.cdc.gov/nchs/births.htm">www.cdc.gov/nchs/births.htm</a> or a state web site.</td>
</tr>
<tr>
<td>National Survey of Children’s Health</td>
<td>Asthma, physical activity, obesity, medical home, parent’s health</td>
<td>Children ages 0 to 17 years old</td>
<td>The federal Maternal and Child Health Bureau and CDC collaborate to collect national and state data on child well being, including physical and emotional health, social context of family, school, and neighborhood in 2003-04, 2007-08, and 2011-12. <a href="http://www.childhealthdata.org/">www.childhealthdata.org/</a> includes a survey of children with special health care needs. Some states have their own child health survey, such as a callback to eligible BRFSS respondents.</td>
</tr>
<tr>
<td>Behavioral Risk Factor Survey</td>
<td>Cholesterol, hypertension, chronic conditions, tobacco use, alcohol use, arthritis, physical activities, fruits and vegetables eaten</td>
<td>Adults 18 and older</td>
<td>CDC and states collect health conditions, preventive practices, and risk behaviors via a telephone interview of adults identified by and sampled from telephone numbers, since 1984. Core questions are asked either every year or rotate every other year. The majority of the core questions are related to chronic disease epidemiology, and a few are related to general health. <a href="http://www.cdc.gov/brfss/">www.cdc.gov/brfss/</a></td>
</tr>
<tr>
<td>National Adult Tobacco Survey</td>
<td>Tobacco use, initiation, quit attempts, media exposure, secondhand smoke exposure</td>
<td>Adults 18 and older</td>
<td>CDC via a contractor interviews a stratified sample of adults that provides state and national estimates, including tobacco-related disparities, related to CDC’s goals for tobacco prevention and control. <a href="http://www.cdc.gov/tobacco/data_statistics/surveys/nats/">www.cdc.gov/tobacco/data_statistics/surveys/nats/</a> For a comparison of tobacco surveys, see: <a href="http://www.cdc.gov/tobacco/data_statistics/surveys/pdfs/surveys-brochure.pdf">www.cdc.gov/tobacco/data_statistics/surveys/pdfs/surveys-brochure.pdf</a></td>
</tr>
<tr>
<td>Pregnancy Risk Assessment Monitoring System</td>
<td>Pre-pregnancy weight, Body Mass Index, gestational diabetes, Breastfeeding, tobacco use</td>
<td>Women of reproductive age who gave birth recently</td>
<td>CDC and 40 states collect maternal attitude and experiences before, during, and shortly after pregnancy by sampling birth certificates. <a href="http://www.cdc.gov/prams/">www.cdc.gov/prams/</a></td>
</tr>
<tr>
<td>Death Certificates</td>
<td>Mortality due to chronic diseases, tobacco</td>
<td>All ages</td>
<td>State vital records units collect causes and factors (like tobacco) contributing to the death and use these data to estimate life expectancy of people with chronic diseases. <a href="http://www.cdc.gov/nchs/deaths.htm">www.cdc.gov/nchs/deaths.htm</a> or a state web site.</td>
</tr>
</tbody>
</table>
Table 7-3. Clinical Registries of Specific Chronic Diseases

<table>
<thead>
<tr>
<th>Source</th>
<th>Disease</th>
<th>Overview</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Program of Cancer Registries</td>
<td>cancer</td>
<td>CDC administers funding to state registries in 45 states that collect data on the cancer occurrence, type, extent, and location (body organ or system), the type of initial treatment, and outcome. These registry jurisdictions cover 96% of the U.S. population. <a href="http://www.cdc.gov/cancer/npcr/">www.cdc.gov/cancer/npcr/</a></td>
</tr>
<tr>
<td>Surveillance, Epidemiology and End Results (SEER) Program</td>
<td>cancer</td>
<td>The National Cancer Institute collects and publishes cancer incidence and survival data from population-based cancer registries covering about 28% of the U.S. population. <a href="http://www.seer.cancer.gov/">www.seer.cancer.gov/</a></td>
</tr>
<tr>
<td>Paul Coverdell National Acute Stroke Registry</td>
<td>stroke</td>
<td>State registries collect data on adults ages 18 and older who have a clinical diagnosis of acute ischemic stroke, intracerebral hemorrhage, subarachnoid hemorrhage, or transient ischemic attack. The purpose is to improve quality of care and thereby reduce premature disability and death due to stroke. As of July 10, 2013, CDC funds 11 states: Arkansas, California, Georgia, Iowa, Massachusetts, Michigan, Minnesota, New York, North Carolina, Ohio, and Wisconsin. <a href="http://www.cdc.gov/DHDSP/programs/stroke_registry.htm">www.cdc.gov/DHDSP/programs/stroke_registry.htm</a></td>
</tr>
</tbody>
</table>

CDC and the National Cancer Institute provide cancer statistics at [http://apps.nccd.cdc.gov/uscs/](http://apps.nccd.cdc.gov/uscs/) and dynamic state profiles at [http://statecancerprofiles.cancer.gov/](http://statecancerprofiles.cancer.gov/) States have cancer registries and also provide statistics. These cancer registries might participate in the programs described in the table below of example clinical registries that provide data on specific chronic diseases.

**Health Care Data Sources**

An example of health care data is the administrative claims or billing data for health care or health system records. This can be claims data submitted by hospitals or outpatient providers for reimbursement for the health care services that they provide or it can be the other side of the same business transaction. It can be claims data reimbursed by the payers of health care services: private health plans or health insurance companies or the federal government (the Center for Medicaid and Medicare Services). Claims or billing data include basic demographics, dates of service, diagnoses, procedures, and possibly charges (the list price of a service), cost, or reimbursed costs. The claims or billing data must provide information on the standard Uniform Billing form, the 2004 version (“UB-04”) required by the Centers for Medicare and Medicaid Services for reimbursement. Diagnoses are coded using the International Classification of Diseases, Ninth Version, Clinical Modification (ICD-9-CM). No earlier than October 1, 2015, hospitals must use the Tenth Version (ICD-10-CM) codes to report required diagnoses when they submit claims for reimbursement by the federal government. ICD-10-CM is a completely different coding scheme from the previous version. These administrative billing data exist in different collections or data
sets, at the national level. Several national sources do not provide state-specific results, because they are based on a representative sample of all claims for a specific type or setting of care, such as care provided in emergency departments. For example, the National Hospital Discharge Survey was a national probability sample survey of discharges from nonfederal short-stay hospitals or general hospitals in the United States. It is now combined with the National Hospital Ambulatory Medical Care Survey to create the National Health Care Survey.\(^91\)

Many states have electronic sources of hospital discharges, emergency department visits, observation visits, and outpatient surgeries. The organization responsible for these data sources can vary from state to state: a state government agency, a private hospital trade association in the state, or a quasi-governmental agency. These data sets can be useful to describe health care utilizations rates for specific chronic diseases. Another example of how to use these data sources is to assess the need for improved chronic disease self-management, based on high rates of emergency department visits for diabetes. Challenges using these data sets and data limitations exist. Using these types of data sources takes some training. Some data sources have only charge data, not cost data, and cost-to-charge ratios can be difficult to get. Some of these claims data sources lack a single, unique person identifier, making it difficult to change the unit of analysis from visits or admissions to persons. The primary diagnosis or main reason for treatment can be difficult to determine. Residents living near state borders might receive treatment out of state. As the lead chronic disease epidemiologist, you might want to know about co-morbidity indexes that can be used with administrative data, such as the Charlson Comorbidity Index and the Elixhauser Comorbidity Measure, to group the detailed ICD codes into meaningful clinical morbidities.

A state’s all-payer claims database (APCD) compiles claims data from private and public health insurance payers to provide comprehensive data of costs and service use in a state. The APCD Council website provides information about states’ implementation of an all-payer claims database and related resources: [http://www.apcdcouncil.org/](http://www.apcdcouncil.org/)

Through the Affordable Care Act, there are incentives to use electronic health records in health care. In addition to being used to improve care of individual patients with chronic diseases through automated reminders to physicians and supportive decision tools, electronic health records might improve electronic reporting to state and local public health for notifiable conditions or reportable conditions and/or reporting to state registries for cancer, stroke, or diabetes.\(^92\) The caution is that both the field of public health and health care have limited IT workforce, outdated and/or customized data systems without interoperability, and many demands on existing staff. Wisconsin’s Division of Public Health has the capability to receive cancer reports through

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electronic health records. Local demonstration projects on meaningful use of electronic health records provide promise. In Minnesota, they linked pediatric-prescribed asthma action plans to the appropriate school nurse for students in their schools. The use of electronic health records for public health is still an emerging opportunity and requires you as the lead chronic disease epidemiologist to keep abreast of changes in this field. For example, look for the future results of this planned study in New York City to use electronic health records in six outpatient clinics to improve diabetes screening, follow-up and management.

Table 7-4. Health Care Data Sources that Provide State Estimates

<table>
<thead>
<tr>
<th>Source</th>
<th>Examples of interest</th>
<th>Brief Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>State hospital inpatient discharges</td>
<td>Counts and rates of admissions for specific chronic diseases</td>
<td>Administrative claims of information based on the national Uniform Billing form (UB-04)</td>
</tr>
<tr>
<td>State Emergency Department visits</td>
<td>Counts and rates of visits for acute complications of asthma or diabetes</td>
<td>Administrative claims of information based on the national Uniform Billing form (UB-04)</td>
</tr>
<tr>
<td>State Emergency Medical Services</td>
<td>Ambulance trip reports for stroke or heart attacks</td>
<td>This data source might match the national standards for emergency medical services information system. See <a href="http://www.nemsis.org">www.nemsis.org</a></td>
</tr>
<tr>
<td>Medicare, Medicaid, and State Children’s Health Insurance</td>
<td>Enrollment by demographics, number of providers by county, diagnosis of chronic conditions, use of clinical and dental services (e.g., mammography screening)</td>
<td>The federal Centers for Medicare and Medicaid Services has publicly available data on beneficiaries, claims, providers, and clinical care.</td>
</tr>
<tr>
<td>HEDIS performance measures on health plans</td>
<td>Blood pressure control, comprehensive diabetes care, beta-blocker treatment after a heart attack, breast cancer screening, weight/BMI assessment, immunization status</td>
<td>Healthcare Effectiveness Data and Information Set (HEDIS): The National Committee on Quality Assurance collects 76 performance measures on health plans through surveys, medical charts, and insurance payments for inpatient and outpatient services.</td>
</tr>
<tr>
<td>MEPS</td>
<td>Dental and health insurance coverage, use of clinical and dental services and costs by demographics and source of payment</td>
<td>Medical Expenditure Panel Survey (MEPS) describes the cost and use of health care and health insurance coverage. <a href="http://meps.ahrq.gov/mepsweb/">http://meps.ahrq.gov/mepsweb/</a> State data available when its sample is large.</td>
</tr>
<tr>
<td>HCUP</td>
<td>Cost-to-charge ratios,</td>
<td>Healthcare Cost and Utilization Project (HCUP) contains state and national data on inpatient care.</td>
</tr>
</tbody>
</table>

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A downloadable file to translate ICD-9-CM codes into chronic vs. non-chronic conditions, downloadable software (2 SAS programs) that identify comorbidities using ICD-9-CM codes and the Elixhauser comorbidity scheme.


**Use Chronic Disease Indicators for Surveillance or Guidance**

The Chronic Disease Indicators reflect the collaboration of CSTE, the National Association of Chronic Disease Directors, and CDC’s National Center for Chronic Disease Prevention and Health Promotion. They comprise a cross-cutting set of 124 measures developed by consensus and based on importance to public health practice and data availability. States can use the Chronic Disease Indicators to develop state- and local-level chronic disease surveillance systems, to plan programs to target at risk populations, and to improve program evaluation. The indicators also enable public health jurisdictions to uniformly define, collect, and report data on conditions and their risk factors that fall into 18 topic groups: alcohol; arthritis; asthma; cancer; cardiovascular disease; chronic kidney disease; chronic obstructive pulmonary disease; diabetes; immunization; nutrition, physical activity, and weight status; oral health; tobacco; overarching conditions; disability; mental health; older adults; reproductive health; and school health.

The data sources for the chronic disease indicators include: the Behavioral Risk Factor Surveillance System (BRFSS), state cancer registries, the American Community Survey (ACS), birth and death certificates data in the National Vital Statistics System (NVSS), the State Tobacco Activities Tracking and Evaluation System, the United States Renal Data System, the Youth Risk Behavior Surveillance System, the Pregnancy Risk Assessment Monitoring System, the Alcohol Epidemiologic Data System, the Alcohol Policy Information System, alcohol policy legal research, the National Survey of Children’s Health, State Emergency Department Databases, State Inpatient Databases, the Centers for Medicare and Medicaid Services Chronic Condition Warehouse and the Medicare Current Beneficiary Survey, the U.S. Department of Agriculture, the CDC School Health Profiles, Achieving a State of Healthy Weight, Maternal Practices in Infant Nutrition and Care, the Breastfeeding Report Card, the Health Resources and Services Administration Uniform Data System, the National Immunization Survey, and the Water Fluoridation Reporting System.

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Assure Capacity in Mandated Maternal and Child Health Surveillance

Title V of the Social Security Act was signed into law in 1935 to promote maternal and child health nationwide. In 1981, funding to states under this federal legislation was converted into the Title V Maternal and Child Health Services Block Grant, a program that provides funding to 59 states and other U.S. jurisdictions to improve the health and well-being of:

- Pregnant women, mothers and infants aged ≤ 1.
- Children and adolescents.
- Children and youth with special health care needs.

Every five years, states receiving this funding must develop a comprehensive statewide needs assessment with stakeholder input. The results from this assessment are critical for program planning, targeting services, and identifying state-specific priorities and performance measures. States and other jurisdictions report annually on their program activities and performance on 18 national performance measures, nine health systems capacity indicators, six national outcome measures and 12 health status indicators. Additionally, states develop individual performance and outcome measures addressing identified priority areas and unique needs based on the state’s five-year needs assessment.

The Maternal and Child Health programs in states commonly use the following data sources:

- birth certificates,
- the National Survey of Children’s Health,
- the National Survey of Children with Special Health Care Needs,
- the Pregnancy Risk Assessment and Monitoring System,
- Title X funded family planning clinics’ data,
- hospital discharge data,
- Medicaid claims data,
- Population data sources such as the U.S. Census

A guidance document for performance measurement is at https://mchdata.hrsa.gov/TVISReports/ and a searchable database on the 18 national performance measures is available at https://mchdata.hrsa.gov/TVISReports/MeasurementData/MeasurementDataMenu.aspx

Below is an example indicator.

**National Health Status Indicator Measurement for Maternal and Child Health**

National Health Status Indicator 1A: Percent of live births weighing less than 2,500 grams.

Numerator: Number of resident live births weighing less than 2500 grams.
Denominator: Number resident live births in the state in the reporting period.
Statistic: Percent

In addition to the indicators above, there are 45 preconception health indicators in 11 domains, including domains of tobacco, alcohol, and substance abuse; chronic conditions (hypertension, asthma, diabetes); nutrition and physical activity (fruits and vegetables, folic acid, overweight,
obesity, pre-pregnancy overweight and obesity, recommended physical activity); and mental health. The sources are:

- Behavioral Risk Factor Surveillance System (BRFSS)
- Pregnancy Risk Assessment Monitoring System (PRAMS)
- National Sexually Transmitted Diseases Database (NSTD)
- National Vital Statistics System (NVSS)

The Association of Maternal and Child Health Programs, in collaboration with experts in the field (including staff from Health Resources and Services Administration’s (HRSA) Maternal and Child Health Bureau, state health departments, and CDC), developed life course indicators to measure states’ progress as they use a life course framework to guide their programs. The final set of 59 standardized life course indicators encompass 12 categories: childhood experiences, community health policy, community wellbeing, discrimination and segregation, early life services, economic experiences, family wellbeing, health care access and quality, mental health, organizational measurement capacity, reproductive life experiences, and social capital. Explore the set of indicators here: [http://www.amchp.org/programsandtopics/data-assessment/Pages/LifeCourseIndicators.aspx](http://www.amchp.org/programsandtopics/data-assessment/Pages/LifeCourseIndicators.aspx)

Understanding Oral Health Surveillance

Healthy People 2020 Objective OH-16 calls for all states and the District of Columbia to establish an oral and craniofacial health surveillance system. In 2012, CSTE approved revised indicators for the National Oral Health Surveillance System indicators. A 2013 report provides a framework for indicators in a state surveillance system, core elements of a state oral health surveillance plan, and an operational definition for measuring that states have an oral health surveillance system.

A collaborative effort of CDC’s Division of Oral Health, the Association of State and Territorial Dental Directors and CSTE, this surveillance system monitors the burden of oral disease, the use of the oral health care delivery system, and the status of community water fluoridation on the national and state levels. Fundamental revisions in this system align with Healthy People 2020 objectives for oral health and include data that cover population groups from kindergarten through older adults and from general populations to at-risk subgroups such as low-income, pregnant, and diabetic populations. As a result, state oral health programs can monitor state progress towards Healthy People 2020 objectives. This revised, expanded system has 34 indicators grouped within 12 indicator concepts, including dental visits, teeth cleaning, tooth loss, water fluoridation, caries, untreated tooth decay, dental treatment needs, preventive dental visits,

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dental sealants, dental treatment visits, school-based health center dental services and oral and pharyngeal cancer.

**Oral Health Basic Screening Survey**

The Basic Screening Survey is a standardized set of surveys on observed oral health of participants. The Association of State and Territorial Dental Directors with technical assistance from CDC developed these surveys. They collect self-report or observed information on age, gender, race and Hispanic ethnicity, and self-report information on access to care for preschool, school-age, and adult populations. The most common administration of this survey in states is among 3rd grade students. The surveys are cross-sectional and descriptive. In the observed oral health survey, dentists and dental hygienists, (or other appropriate health care workers in accordance with state law) record gross dental or oral lesions. The examiner records presence of untreated cavities and urgency of need for treatment for all age groups; caries experience (treated and untreated decay) for preschool and school-age children; the presence of sealants on permanent molars for school-age children; and edentulism (no natural teeth) for adults. States might use one or more of the surveys to obtain oral health status and dental care access data for monitoring Healthy People 2010 objectives. The surveys come with training materials. The Association of State and Territorial Dental Directors provides technical assistance on sampling and analysis using the standard protocol. Some states collect height and weight as part of this observed survey.

**Source:** CDC Oral Health Resources website, [www.cdc.gov/nohss/DSMain.htm](http://www.cdc.gov/nohss/DSMain.htm)

The data sources for the National Oral Health Surveillance Indicators are:

- Basic Screening Survey
- Behavioral Risk Factor Surveillance System
- Centers for Medicare and Medicaid Services
- National Assembly on School-Based Health Care
- National Survey of Children’s Health
- Pregnancy Risk Assessment Monitoring System
- Surveillance, Epidemiology and End Results and National Program of Cancer Registries
- Water Fluoridation Reporting System

The full list of indicators and their sources is at [www.cdc.gov/nohss/](http://www.cdc.gov/nohss/)

Below is an example indicator.

**Example Indicator Measurement**

<table>
<thead>
<tr>
<th>Indicator 1A: Percentage of adults 18 years and older with a dental visit in the past year.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Numerator: Number adults ≥ 18 years reporting they had a dental visit in the past year.</td>
</tr>
<tr>
<td>Data Source: BRFSS</td>
</tr>
<tr>
<td>Denominator: Number adults ≥ 18 years responding to this question on the BRFSS.</td>
</tr>
<tr>
<td>Data Source: BRFSS</td>
</tr>
<tr>
<td>Statistic: Percent</td>
</tr>
</tbody>
</table>
Using the Healthy People Objectives as Targets

The Healthy People Objectives for 2020 provides a warehouse of national baseline data on the objectives from a variety of sources.\textsuperscript{101} Healthy People 2020 provides standard data definitions and conceptual information about the indicators or objectives. Including national objectives with state chronic disease data can elevate the importance of a chronic disease problem and give a national comparison for state results. The Healthy People 2020 goals or targets can become the state goal, depending upon the state baseline results.

Find Additional Indicators and Interventions at the Health Indicators Warehouse

At the Health Indicators Warehouse, the National Center for Health Statistics provides public access to community health indicators from initiatives, such as the Healthy People 2020, county health rankings, and community indicators from the Centers for Medicare and Medicaid Services.\textsuperscript{102} The purpose is to improve understanding of a community’s health status and determinants and links indicators with evidence-based interventions. Search by topic, by geography, and/or by initiative. Topics include chronic diseases, maternal and infant health, oral health, health behaviors, and health outcome. For example, if you wanted to know about stroke mortality in your state and initiatives to prevent it or if you wanted to know the percent of Medicare beneficiaries with arthritis in a selected state, this warehouse is helpful. The content and purpose of this warehouse reflect its partners.

- Centers for Medicare & Medicaid Services
- Department of Health and Human Services:
  - Office of the Deputy Secretary
  - Office of Adolescent Health
  - Office of Disease Prevention and Health Promotion
  - Office of Minority Health
  - Office of the Assistant Secretary for Planning and Evaluation
- Health Resources and Services Administration


Summary

Understanding the history, purpose, and indicators used for surveillance of chronic diseases, maternal and child health, and oral health builds your capacity as a lead chronic disease epidemiologist in assessment and analysis and can fuel your systems thinking. Cross-training and collaboration on using multiple data systems can expand capacity without adding staff.103

- **Surveillance:** In general, you as the lead chronic disease epidemiologist need to become an expert in interpreting results from Behavioral Risk Factor Surveillance System and any chronic disease-specific data system in your state, such as a cancer registry. To further integration efforts in your state, add a working knowledge of relevant health care data, the basic screening survey for oral health, and the Pregnancy Risk Assessment and Monitoring System. Learn about successes in using data to drive action from other states, the data coordinators in your state, and through CDC and CSTE websites. Use these data sources to identify tested questions that might be appropriate to add to the Behavioral Risk Factor Surveillance System in your state.

- **Communication:** Use multiple data systems to communicate a more comprehensive picture of chronic disease issues across the life span and to highlight specific opportunities to prevent and control chronic diseases. Disseminate relevant chronic disease indicators to colleagues addressing oral health and maternal and child health. The relevancy might simply be the same target age group, such as obesity prevalence in school-age children.

- **Consultation:** Meet the state coordinators of the Behavioral Risk Factor Surveillance System, the oral health surveillance system, and the maternal and child health measures. Ask them to read this chapter and discuss their work with you. Remember that they might not be located in your part of the department or anywhere in your department. Consult with them to learn and to expand the use of their data systems, which helps them justify the continued investment in their data system. Share ideas with them about potential ways to enhance the system and creatively maintain funding. Identify together ways to leverage resources and cross promote data results.

Chapter 8: Data Interpretation and Dissemination

At the heart of chronic disease epidemiology is the quest to understand past disease trends and their association with potential risk and protective factors so to inform public health decisions and actions. This mission requires the development of appropriate methods to measure the impact of disease trends and associated risk factors. This data-driven approach is the foundation of evidence-based public health (Chapter 5). Data collection is just the first step, followed by analysis and dissemination of surveillance data that address real-world problems. This chapter covers key concepts and tips common for analysis and dissemination of chronic disease data, though not unique to it. As the lead chronic disease epidemiologist, your statistical knowledge, your skill in assessing bias in observational data, and your understanding of the strengths and limitations of each surveillance method (Chapter 7) and their impact on the resulting data will be crucial to appropriately interpreting data results. In other words, you will be able to objectively state what the results mean and do not mean. In addition to data interpretation, you will synthesize results to identify what public health actions the results support. You will translate the results into everyday language that policy makers and other decision makers can readily use.

Review Concepts Critical for Analyzing and Interpreting Data

CDC provides an online, self-study course in the principles of epidemiology in public health practice. Its six lessons and glossary cover descriptive and analytic epidemiology (lesson 1), disease concepts, surveillance (lesson 5), and applied biostatistics (lesson 3 on measures of risk). The website of the National Association for Public Health Statistics and Information Systems provides statistical measures commonly used with birth and death data. University of California, Los Angeles shares a good resource for selecting the most appropriate statistical test to use. For convenience, defined below are a few core statistical measures and concepts.

- **Type of measurement: Quantitative** data are information that can be measured (counted) and therefore can be represented with numbers. Chronic disease epidemiologists often use quantitative data. In contrast, **qualitative** data cannot be measured though it can be described or observed, such as colors or textures. Therefore, qualitative data represents information in non-numeric form, such as narrative descriptions in the form of text, audio words, or images.

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Examples of qualitative data more common in public health are focus group notes or answers to open-ended interview questions. Qualitative data can provide insight or context that fills a gap in the quantitative data. However, qualitative findings will not be generalizable beyond the group who provided the information.

- **Measuring data quality:** Two qualities of measurement necessary for understanding and interpreting accurately data results are validity and reliability. **Validity** is the degree to which the measurement actually measures what it is intended to measure. **Reliability** refers to the degree to which a measurement produces the same values when identical measurements are repeated in the same population. If a measure is not valid, then what is being measured is not known. If a measure is not reliable, then one cannot measure changes over time.

- **Measuring magnitude of events or disease occurrence in a population:** **Incidence rate** is the rate of new cases of a disease or condition among a population over a defined period of time. Incidence rate is also a proportion, because the persons in the numerator are also in the denominator. A commonly used incidence rate is a death rate from the state mortality system of death certificates. **Prevalence** is the rate of existing cases of a disease, condition or behavior (e.g., tobacco use) among a population at a point in time or over a defined period of time. The most commonly used chronic disease prevalence rates come from BRFSS. BRFSS prevalence estimates can approximate the current (or historical) burden of a disease or risk factor in a population but not usually the number of new cases. Prevalence is a function of incidence and duration of a condition. Both can be used as measures of risk. **Adjusted rates** are rates that have been standardized in such a way to allow for fair comparisons of rates over time or among different populations defined by the geography where they reside. The most common in epidemiology is age-adjusted rates, because the rate of chronic diseases increases with increasing age. The direct method of age adjustment: Age-specific rates for a population at a particular time and place are applied to a standard age distribution, such as the U.S. population in 2000. Age-specific rates for a second population are applied to the same standard age distribution. In effect, the two resulting artificial or hypothetical rates allow for a fair comparison, because the resulting rates are independent of the underlying age distribution of the population they represent.

- **Measuring change in risk:** **Relative reduction** is the percent change from the baseline period compared to the next period of interest (e.g., 50% relative decrease from a prevalence of 20% in 2000 to 10% in 2010). It can also be the percent change among the experimental group compared to the control group. It is calculated as follows:

\[
\text{Relative reduction} = \frac{(\text{Event Rate among Experimental Group} - \text{Event Rate among Controls})}{\text{Event Rate among Controls}}
\]

or

\[
(\text{Baseline Rate} - \text{Current Rate}) \div \text{Baseline Rate}
\]

**Absolute reduction** is the difference between the rate during the baseline period or among the control group and the rate during the current period or among the experimental group (e.g.,
10% absolute difference from the prevalence of 20% in 2000 to 10% in 2010, sometimes described as a 10-point change).

- **Examining trends** is a basic analysis of surveillance data by time to detect changes in incidence or prevalence of risk and protective factors and health outcomes. Assess if the change in risk is an artifact of an increase in population size, improved diagnostic procedures, and/or enhanced reporting and other reporting biases.

- **Measures of association** between an exposure or risk factor and a health outcome include risk ratio (relative risk), rate ratio, odds ratio, and population attributable risk. An association is any observed relationship or pattern between measured quantities. An association is not the same as causation.107 Risk ratio is the ratio of incidence proportions of two groups (the percentage of persons with a disease in group one divided by the percentage of persons with a disease in a second group). The rate ratio is the ratio of incidence rates of two groups. Odds ratios provide a reasonable approximation of a risk ratio when the study design is a case-control study. In a case-control study, one cannot calculate risk, because the size of the population from which the cases (the persons with the outcome of interest) is not known. Confounding is the distortion of an association between an exposure (risk factor) and a health outcome by a third variable related to both the exposure and the outcome. Interaction is modification of the effect of the exposure on the outcome by a third variable. For example, the risk of mesothelioma from exposure to asbestos greater among smokers than non-smokers. Population attributable risk measures the public health impact of an association between an exposure and outcome. Also known as attributable proportion or attributable risk percent, it represents the expected reduction in disease if the exposure could be removed. The definition is the difference between risks for the exposed group and unexposed group divided by the risk for the exposed group times 100%. For example, Colorado analyzed the population attributable risks of maternal smoking and inadequate weight gain during pregnancy on low birth weight.108

- **Statistically significance** is a measure of how likely a result could have occurred by chance alone, and a confidence interval is a range of values for a measure or estimate (e.g., rate or odds ratio) constructed so that the range has a specified probability of including the true value of the measure in the population. Often the probability, which is selected in advance of running the calculations, is 95 percent. For example, if an epidemiologist took 100 random samples from the population and each time measured obesity in the sample, 95 times out of a 100, the true obesity prevalence in the population would be within the 95% confidence interval. If the confidence intervals for estimates (in the same population in two time periods or two populations in the same time period) do not overlap then these two estimates are statistically significantly different. However, this difference might not be clinically relevant or

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meaningful in practical terms. Also, using confidence intervals to test for statistical significance is sometimes a conservative approach.

Understand Concepts Critical for Disseminating Data Results

There are circumstances where you as the lead chronic disease epidemiologist cannot or should not release data results. Not releasing data is referred to as “data suppression”. The two main reasons to suppress data are: 1) to protect the confidentiality of the person or persons and 2) to prevent the use of unreliable data or low quality data. To protect confidentiality, follow the confidentiality guidelines and data use agreements—standards established by the health department, data source, or surveillance system to protect the identity of the individuals or jurisdictions represented within the data (Chapter 6). Public health practitioners can be held personally liable for not following these standards. The exact threshold for suppression varies in confidentiality guidelines and might be based solely on the numerator or both the numerator and the denominator in an analyzed table of results. For example, a confidentiality guideline could specify that any count in a table that is less than 5 must be suppressed, meaning deleted from the table of results, regardless of the total count in the table or the total population the analyzed results represent. Some guidelines further specify that if the reader can calculate the number suppressed from the table of results that more information must be suppressed or further aggregated. To prevent the use of low quality data, there are sample size guidelines—standards established by the surveillance system to ensure that only representative (and reliable) data is shared. For example, the Behavioral Risk Factor Surveillance System suppresses data with an unweighted sample size of the denominator is less than 50 respondents or the relative standard error is greater than 0.3. In addition, caution is warranted in interpreting estimates based on cell sizes (numerators) less than 50.

Translate Data for Optimal Messaging to Your Intended Audience

For data to effectively drive action, the data results from surveillance systems must be easy for staff to use appropriately and easy for the public to understand. Your role is to determine the audience(s) for the data results and their specific needs, select appropriate formats for sharing the results, identify the key messages for each audience, and share information accordingly. You are translating numeric, statistical information into everyday language while also interpreting and revealing the meaning of the results. Telling the results as a story that frames the issue and uses social math provides the kind of everyday language that busy professionals (colleagues, policymakers) immediately grasp and will use.

Frame your information to tell a story

The London-based data-journalist and “information designer” David McCandless advises data purveyors to “design information so it makes more sense, tells a story, and allows us to focus only
on information that is important.” Answer these questions before developing your message from the data, a message that connects the problem, solution, values, and action.

- What story do the data tell? What problem and solution, if any, do the data suggest?
- What is your end game? What question were you trying to answer with the data analysis? What is your call to action?
- Who is your audience? What do they value? What is their context? What decisions are they facing?
- Numeracy or statistical literacy of the audience? Can they translate percentages and rates? If not, the data will need to be presented as simply as possible, in a clear language with compelling context and visual displays of the results that would tell the same story, if the words were removed. What is your understanding of the concept and meaning, not just the tool of data analysis and the recipe for calculating a rate? Do you understand the concept well enough to tell it simply?

Use social math and framing to help tell your story

Social math is “the practice of translating statistics and other data so they become interesting to the journalist and meaningful to the audience.” As outlined in CDC’s *Framing Guide for Communicating about Injury*, there are several steps for creating social math and a compelling story:

1. Consider the message frame. For example, CDC’s frame for those who work in the field of injury is “We want a society where people can live to their full potential.” This frame is a value that you and the audience have in common. When selecting a frame, consider what you want to accomplish and whether you can make interesting connections, comparisons or metaphors.

2. Make a strong and dramatic statement of the problem.
   - Select relevant examples appropriate for the target audience.
   - Make the statistic meaningful to the audience. It can be effective to break data down by time (e.g., 400,000 deaths per year) and by place to localize the information as much as possible. However, do not provide a long list of statistics about the problem. People want to know about the solutions, what they cost, and how they will get done.
   - Find useful comparison statistics, such as a statistic about a familiar thing. For example, compare the daily individual cost of a program to the cost of a daily latte coffee. The comparison can be dramatic or unusual. However, avoid invalid, unfair comparisons.

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3. Get to the solution sooner, and use positive, action-oriented statements about the solution.
   - Reinforce the science without jargon.
   - If personal responsibility and/or community action are common values, tie the solution to them.
   - Ensure that the message has a call to action and engages the audience to act.

   - Are 100% accurate.
   - Make sense and are related.
   - Are appropriate for the audience.
   - Are married to the story.
   - Are visual, if possible.
   - Are dramatic.
   - Engages the audience in fixing the problem.
   - Do not depict mayhem.
   - Are used sparingly.

To recap, the steps to arrive at an effective story that connects the problem, solution, values, and action: Consider the frame, relevant examples, statistics, and comparison; limit what to present; avoid invalid, unfair comparisons; check facts and visuals.

*Present effectively*

Known for his engaging presentation, former Apple CEO Steve Jobs used a similar approach as described above. His ten favorite public speaking tips “to be insanely great in front of any audience” are:\footnote{Gallo C. *The Presentation Secrets of Steve Jobs: How to Be Insanely Great in Front of Any Audience.* New York, NY: McGraw-Hill Books, 2010.}

1. Plan your presentation with pen and paper.
2. Simplify complex information.
3. Tell a story with a villain and a hero. [This tip might not always work for public health. Public health professionals and government officials are careful in describing the problem and the potential solutions. They are careful not to demonize or victimize people and businesses.]
4. Personalize benefits. The audience needs to know “what’s in it for me?”
5. Stick to the rule of three. It is easier for people to remember three key points. [Three verbal points are common in U.S. culture. A story has a beginning, middle, and end. Jokes have three repetitions. Sermons have three points.]
6. Evoke a higher sense of purpose.
7. Create visual slides.
8. Make numbers meaningful.
9. Use plain English.
10. Practice before you present.

Consider trying presentation software such as Prezi, which allows a viewer to see a whole visual representation before the embedded detail slides. The online presentation tool is at http://prezi.com/ and has tips and examples to help you organize your ideas and present your information effectively. Look at the examples listed below for ways to summarize and present data results visually.

Mapping examples

- Central Indiana interactive mapping: http://www.savi.org/savi/QuickInformation.aspx
- Indiana mapping and social networking: www.communitycommons.org
- U.S. County Profiles with maps of life expectancy, obesity, and sufficient physical activity:
  http://www.healthmetricsandevaluation.org/us-health/county-profiles

Data visualization examples

www.indianacancer.org/category/blog/infograph/
www.informationisbeautiful.net/visualizations/
www.gapminder.org/
www.dashboard.imamuseum.org/
http://www.healthmetricsandevaluation.org/tools/data-visualizations
Summary

This chapter reviews key concepts in analyzing, interpreting, and disseminating data and suggests ways to match the data and its message to the intended audience. It focuses on your essential role in surveillance and communication.

- Surveillance: Keep examples of data products and presentation, regardless of the topic, to help you quickly and meaningfully disseminate results of chronic disease surveillance regularly and widely in a variety of formats.

- Communication: If simply communicating complex or statistical information is not your strength, consider one of these suggestions. Read science writers who communicate technical information in everyday language. Review the resources in the chapter as often as needed. Review CDC’s website.

- Consultation: Talk to your health communication specialist in your department.
Chapter 9: Technical Assistance and Related Programs

Chronic disease epidemiologists have a strong technical assistance and support network available to them. Fortunately, whether you are a lead chronic disease epidemiologist, a senior epidemiologist, or an entry-level epidemiologist who focuses on one disease, there is help, even with staffing. CSTE, CDC, the National Association of Chronic Disease Directors, the Association of State and Territorial Dental Directors are among the organizations you will turn to time and time again.

Summarized below is information on national organizations and their training programs that can benefit you as the lead chronic disease epidemiologist and/or your organization. This information is mostly from the web sites of the key organizations. Listed first are three key national professional organizations and their fellowship and training programs, then the many CDC-sponsored ones, and finally jointly-sponsored programs in public health informatics.

Council of State and Territorial Epidemiologists (CSTE)
CSTE is a professional membership organization representing state and territorial public health epidemiologists. It works to establish more effective relationships among state and other health agencies and provides technical advice and assistance to partner organizations and to federal public health agencies, such as CDC. CSTE members have surveillance and epidemiology expertise in a broad range of areas, including chronic disease, maternal and child health, occupational health, infectious diseases, immunization, environmental health, and injury control. The association promotes the successful use of epidemiologic data to guide public health practice and improve health. It accomplishes this mission by supporting the use of effective public health surveillance strategies and good epidemiologic practice through training, capacity development, peer consultation, development of practice standards, and advocacy for resources and science-based policy.

As a lead epidemiologist at a state health department, you can benefit from all that CSTE provides: free professional development webinars, free referral to experts and state contacts for each of the specialty areas of epidemiology, position statements, white papers, work groups, and competencies and capacity assessment tools.

For more information, go to: www.cste.org


CDC/CSTE Applied Epidemiology Fellowship

CSTE—in collaboration with CDC, the Association of Schools of Public Health, and the Health Resources and Services Administration—has established the Applied Epidemiology Fellowship to train recent master- or doctoral-level graduates with a degree in epidemiology or related field who are interested in public health practice at the state or local level. This fellowship has three core goals:

- Providing service to the sponsoring agency.
- Creating and training a core group of public health workers.
- Strengthening capacity in applied epidemiology across public health institutions.

Fellows receive a high quality experience through two years of on-the-job training at a state health department under the guidance of an experienced mentor. The fellowship provides rigorous, formal training. Fellows have flexibility in pursuing particular interests and in meeting the needs of the host organization.

National Association of Chronic Disease Directors

This association for professional members serves state and territorial chronic disease program directors. It represents more than 3,000 chronic disease practitioners, advocates for preventive policies and programs, and encourages knowledge-sharing and partnerships for health promotion.

It supports state chronic disease prevention and control by:

- Providing educational and training opportunities.
- Developing legislative analyses, materials, and policy statements.
- Educating policymakers about the importance of funding state chronic disease prevention and control efforts.
- Providing technical assistance and mentoring to state public health practitioners.
- Promoting partnerships among public health practitioners, researchers, health care providers, federal agencies, academia, and private sector entities to pursue common goals.
- Advocating for the use of epidemiological approaches in chronic disease service planning and evaluation.

Its councils address specific chronic diseases, while advancing the professional development of chronic disease staff with common program interests. Like CSTE, this association provides you, as a lead chronic disease epidemiologist, professional growth opportunities. For more information, go to: www.chronicdisease.org
NACDD National Mentorship Program in Applied Chronic Disease Epidemiology

In collaboration with CDC, this mentorship program aims to:

- Enlarge the pool of trained chronic disease epidemiologists at public health agencies.
- Improve the practice of chronic disease epidemiology.
- Increase the development and application of epidemiological science in chronic disease programs and policies.

It pairs experienced mentors with an epidemiologist currently working at a public health agency. Each mentorship lasts six to 12 months and focuses on targeted competencies and projects that the mentee chooses.

Evidence Based Public Health Training

With support from the National Association of Chronic Disease Directors and CDC, the Prevention Research Center in St. Louis offers a four-day course on evidence-based public health, focusing on many of the core competencies for public health professionals adopted by various accrediting bodies. The course is taught through lectures, practice exercises, and case studies, and addresses everything from community assessment to program evaluation.

For more information, go to: http://www.chronicdisease.org/?page=HealthTraining or http://prcstl.wustl.edu/training/Pages/Evidence-Based-Public-Health-Course.aspx

Association of State and Territorial Dental Directors

This professional membership organization represents oral health program directors and staff in state and territorial public health agencies. This association advocates for science-based, dental public health policy and supports members with technical assistance to develop and implement oral health programs and conferences for the dental public health community.

For more information, go to: http://www.astdd.org/

Centers for Disease Control and Prevention (CDC) Programs

Your organization can apply to be a site host for the following fellows and trainees. Your organization benefits by gaining an additional staff member prepared to gain hands-on experience. Alternatively, you can encourage staff to apply to these fellowship and training programs.

State Chronic Disease Epidemiology Assignee Program

The Chronic Disease Epidemiology Assignee Program (formerly the State-Based Epidemiology for Public Health Program Support (STEPPS)) activity was developed to assist states in building
sustainable capacity for chronic disease epidemiology. This program answers the *Healthy People 2020* call for an increase in “the proportion of tribal, state, and local public health agencies that provide or assure comprehensive epidemiology services to support essential public health services.”

It provides health departments with the direct assistance of a full-time, fully trained chronic disease epidemiologist for approximately four years. This CDC employee, usually also a doctorate-level professional trained in applied epidemiology, works in the state public health department. Currently, states fund the assignee through Direct Assistance (DA) from one or several of their CDC funded chronic disease grants. Since 1991, this program has provided staff or salary support to states to build chronic disease epidemiology capacity.

More information on Direct Assistance can be found at [http://www.cdc.gov](http://www.cdc.gov). To request more information, contact CDC at: [http://www.cdc.gov/cdc-info/requestform.html](http://www.cdc.gov/cdc-info/requestform.html)

**Public Health Associate Program**

Sponsored by CDC, the Public Health Associate Program is a competitive, two-year, paid training program for persons with bachelor’s or master’s degree. These associates are assigned to a state, tribal, local, or territorial public health agency and work on prevention alongside other professionals across a variety of public health settings.

For more information, go to [http://www.cdc.gov/phap/](http://www.cdc.gov/phap/)

**Epidemic Intelligence Service (EIS)**

The EIS is a unique two-year, post-graduate training program of service and on-the-job learning for health professionals interested in the practice of applied epidemiology.

The EIS is primarily a post-doctoral level program. Most EIS officers hold PhDs or doctoral degrees in medicine, veterinary science, or dentistry. A small number of non-doctoral applicants with MPHs (nurses) are also accepted into the program. About 75% of EIS graduates remain in public health at CDC or in state or local health departments after completing the program. Many become leaders in public health throughout the world. The EIS program is modeled after a traditional medical residency program with both classroom instruction and experiential learning.

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Classroom instruction includes topics such as applied epidemiology, biostatistics, public health surveillance, scientific writing, working with the media, and emerging public health issues. Each EIS class begins with a one-month course, starting in July each year in Atlanta.

As part of their on-the-job training, EIS officers are required to complete core activities of learning:

- Conduct or participate in a field investigation of a potentially serious public health problem.
- Design, conduct, and interpret an epidemiologic analysis on public health data.
- Design, implement, or evaluate a public health surveillance system.
- Write and submit a scientific manuscript for a peer-reviewed journal.
- Write and submit a report to the *Morbidity and Mortality Weekly Report*.
- Present a paper or poster at the annual EIS Conference.
- Give an oral presentation at CDC’s Epidemiology Grand Rounds or at a national or international scientific meeting.
- Respond appropriately to written or oral public health inquiries.

For more information, go to: [http://www.cdc.gov/eis/](http://www.cdc.gov/eis/)

*Epi-Aid*

If you have worked in infectious disease epidemiology, you might know about this help. States and local agencies can request from CDC epidemiological assistance to respond to emergencies, investigate infectious and environmental disease outbreaks, and quantify impact of diseases. An EIS officer can provide the Epi-Aid or lead a team that includes. Though Epi-Aids rarely address chronic disease issues, CDC did respond to the National Parks Service request to assess parks in terms of the offerings of healthy food and free water within the parks. CDC recruited additional help from state and local chronic disease epidemiologists and trained them to conduct an on-site, standardized observational assessment.

To request an Epi-Aid, your state epidemiologist submits a formal, email request to the EIS Program [EIS@cdc.gov](mailto:EIS@cdc.gov)

For more information, go to: [http://www.cdc.gov/mmwr/pdf/other/su6004.pdf](http://www.cdc.gov/mmwr/pdf/other/su6004.pdf) or [http://www.cdc.gov/nceh/eis/epi_aid.html](http://www.cdc.gov/nceh/eis/epi_aid.html)

*Public Health Informatics*

The Applied Public Health Informatics Fellowship, Informatics Training in Place Program, and Health Systems Integration Program are fellowship programs that provide capacity building
opportunities at health departments in informatics and epidemiology. They are a collaborative partnership between the Association of State and Territorial Health Officers, Centers for Disease Control and Prevention, Council of State and Territorial Epidemiologists, National Association of County and City Health Officials, and the Public Health Informatics Institute.

**Applied Public Health Informatics Fellowship Program** provides a fellowship in applied public health informatics through one year of on-the-job training at a local or state health agency under the guidance of experienced mentors. For more information, go to [http://www.aphif.org/](http://www.aphif.org/)

**The Health Systems Integration Program** places public health practitioners with a strong background in epidemiology or informatics at State, Tribal, Local, and Territorial health departments. Fellows will be involved in activities that address:

1) Community epidemiologic surveillance to support community health needs assessments,
2) The public health interface and use of electronic health records, and
3) Lessons learned from successful public health and primary care professional partnerships.

**Informatics Training in Place Program** provides one year of on-the-job training program in applied public health informatics. This program emphasizes meaningful use of electronic health records and surveillance system improvement. It is for CDC staff as well as state and local health department staff and the applied training is delivered in the workplace. **For more information, go to:** [http://www.cdc.gov/ophss/csels/dsepd的战略-工作队-活动/](http://www.cdc.gov/ophss/csels/dsepd/strategic-workforce-activities/)

For a central site of CDC fellowship, training resources, and continuing education, bookmark: [http://www.cdc.gov/fellowships/CareerInternships.html](http://www.cdc.gov/fellowships/CareerInternships.html)

CDC has also organized fellowship programs and continuing education for public health professionals here: [http://www.cdc.gov/ophss/csels/dsepd/index.html](http://www.cdc.gov/ophss/csels/dsepd/index.html)

*Summary*

This chapter provides you as a lead epidemiologist the means to be a lifelong learner—whether it is through a formal or informal mentorship or though mentoring others.
Summary

The demands of being the lead chronic disease epidemiologist can be huge but so is the reward. You will serve as a subject matter expert on multiple topics. You will perform a variety of duties (especially when short staffed) – as evidenced by the length and broad content of this orientation manual. Continue to seek a balance between the job challenges and meeting your personal needs. Focus on the work that only you can do and on capacity building. Reviewing the role of a lead chronic disease epidemiologist might help you keep that focus.\(^{115}\)

Your role is to:

- Coordinate and conduct chronic disease surveillance
- Disseminate the results regularly and widely in a variety of formats
- Provide epidemiology support as reflected in reports, funding applications, and evaluations
- Coordinate activities and improve epidemiology capacity across individual chronic disease-specific programs
- Serve as the epidemiology point of contact with CSTE and CDC, if appropriate in your state
- Monitor and assess your department’s chronic disease epidemiology capacity and create a strategic plan to improve the capacity

Review Chapters Listed by Essential Functions of a Chronic Disease Epidemiologist

This manual highlighted the three most common essential public health services that you as a lead chronic disease epidemiologist will provide.

1. Surveillance
2. Communication
3. Consultation

To help you use this manual as a reference for continuing learning, the following table shows which chapters contain information on all the essential public health services (except regulation) and their related essential function of a chronic disease epidemiologist.

\(^{115}\) CSTE. Chronic Disease Epidemiology Essential Functions – 2004. 
<table>
<thead>
<tr>
<th>Essential Public Health Services</th>
<th>Chronic Disease Epidemiology Essential Function*</th>
<th>Lead chronic disease epidemiologist</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surveillance</td>
<td>Evaluate changes in disease, health events, and risk factors associated with public health interventions</td>
<td>Review chapter 4 on systems thinking, chapters 5 on evidence-based public health, chapter 6 on data sources and indicators, chapter 8 on data analysis and dissemination</td>
</tr>
<tr>
<td></td>
<td>Ensure surveillance systems meet the key attributes, especially usefulness, data quality, accuracy, and representativeness</td>
<td>Review chapter 6</td>
</tr>
<tr>
<td>Communication</td>
<td>Interpret results for action by decision-makers</td>
<td>Review chapter 8 on data analysis and dissemination</td>
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<td></td>
<td>Identify the population at risk and help create appropriate messages for reaching this population</td>
<td>Review chapter 8</td>
</tr>
<tr>
<td></td>
<td>Ensure that both decision-makers and the target population have all the relevant information necessary to make decisions and take action</td>
<td>Review chapter 3 on integration and collaboration, chapter 4 on the social ecological model and on social determinants of health</td>
</tr>
<tr>
<td>Consultation</td>
<td>Interpret surveillance and evaluation data for decision making</td>
<td>Review chapter 5 on evidence-based public health and chapter 8 on data analysis and dissemination</td>
</tr>
<tr>
<td></td>
<td>Review, synthesize, and interpret research articles on public health strategies and outcomes</td>
<td>Review chapter 5</td>
</tr>
<tr>
<td></td>
<td>Ensure that scientific evidence is appropriately incorporated into program planning and selection of new policies</td>
<td>Review chapter 5</td>
</tr>
<tr>
<td>Evaluation</td>
<td>Design, implement, and coordinate scientifically-sound evaluations of program impacts, including outcomes of health services, health promotion, and disease prevention</td>
<td>Review chapter 5 on evidence-based public health</td>
</tr>
<tr>
<td>Investigation</td>
<td>Collect and correlated data from disparate sources and collaborate with multiple public health and personal health programs and agencies</td>
<td>Review chapter 4 on social ecological model, chapter 7 on data sources, and chapter 3 on integration</td>
</tr>
<tr>
<td>Mobilization</td>
<td>Use the data collected through partnerships to inform community members, policy makers and others, enabling them to craft and implement action plans for solving the defined health problems</td>
<td>Review chapter 3 on integration and chapter 5 on evidence-based public health</td>
</tr>
<tr>
<td></td>
<td>Ensure action plans are based on appropriate interpretation of current data and research-based best practices and include science-based links between interventions and desired outcomes</td>
<td>Review chapter 5</td>
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</table>

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<th>Chronic Disease Epidemiology Essential Function</th>
<th>Mid-level Epidemiologist serving as the lead chronic disease epidemiologist (CSTE Tier 2)</th>
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<td>Innovation</td>
<td>Review scientific literature and collaborate with academic centers and with other public health professionals to develop new approaches for conducting surveillance, investigations, and evaluations, and to design innovative public health interventions with a particular emphasis on prevention.</td>
<td>Review chapter 5 on evidence-based public health and chapter 8 on data analysis and dissemination. Review chapter 5 and chapter 8</td>
</tr>
<tr>
<td>Regulation</td>
<td>---not applicable in terms of regulating others</td>
<td>---not applicable</td>
</tr>
<tr>
<td>Utilization</td>
<td>Collect, analyze and report data on availability, access, and utilization of personal health services and prevention and health promotion programs among population subgroups, including trends over time</td>
<td>Review chapter 3 on integration and collaboration, chapter 4 on systems thinking, and chapter 7 on data sources</td>
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<th>Appendix A:</th>
<th>Eight Sets of Sample SAS Code to Use with BRFSS Data</th>
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<td>Appendix D:</td>
<td>Position Descriptions and Related Workforce Development Resources</td>
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Appendix A: Eight Sets of Sample SAS Code to Use with BRFSS Data

The first sample SAS program uses SAS macros and arrays, SAS proc surveyfreq, proc report and SAS ODS with data from the Behavioral Risk Factor Surveillance Program from 1994-2010 prior to the change in weighting methodology to raking. It labels and weights the data, then outputs the crosstab results into a formatted CVS file. It combines answers of “don’t know” and refused into one missing category. The program selects years 2008-2010 and provides the results as three-year averages. Because of the use of macros, it is easy to add additional variables to generate crosstabs.

*The following SAS program was written by Nisha Kini, Alison Green-Parsons, and Santosh Nazare. Edits were made by Pratik Pandya and Carrie Daniels.*

/*Set libname to reference the folder where you have the dataset*/
Libname BRFSS "M:\2010 Data and Information\";
*Please assign weight variable. Please note that 'weight variable' changes by your requested
variable. Refer to BRFSS Data Dictionary 'User Information' field to check
'Survey Part/Arm'.
e.g. Part A, Part B or Core etc.;
/*We will be using SAS macros in this program. Specify your byvariable here.
I am trying to look at
prediabetes rates and hence my byvariable is prediabetes. Please use the
appropriate byvariable here*/
%let byvar=NEW_PREDiab;
/*Please use the appropriate
weighting variable here. Please look at your state BRFSS
documentation for defining weighing variables*/
%let weightvar=newfinalwt;

*Please assign strata variable;
%let stratvar=_ststr;

*Please assign cluster variable;
%let clustvar=_psu;

*Please give the path(windows directory) for output files;
%let out=S:\-------\Nisha\Diabetes Surveillance Report\SAS\Prediabetes;
proc format;
/*Use proc format to format your variables. By formatting your variables you
will not have a bunch of 0,1,2s
in your output which can be difficult to read and in this way you will reduce
misinterpretation*/
value _EDUCAGf
1 = "Less than High School"
2 = "High School or GED"
3 = "Some post High School"
4 = "College Graduate"
;
value _INCOMGf
1 = "Less than $15,000"
2 = "$15,000 - $24,999"
3 = "$25,000 - $34,999"
4 = "$35,000 - $49,999"
5 = "More than $50,000"
;
value _RACEG2f
 1 = "Non-Hispanic White"
 2 = "Non-White or Hispanic"
;
value Sexf
 1 = "Male"
 2 = "Female"
;
value _AGEG_f
 1 = "18-24 yrs"
 2 = "25-34 yrs"
 3 = "35-44 yrs"
 4 = "45-54 yrs"
 5 = "55-64 yrs"
 6 = "65+ yrs"
;
value new_diabetesf
 1="yes"
 2="no";

value totf
 1= "All";

run;
data d;
set BRFSS.mdrive_me9410_s8;

/*The input dataset contains BRFSS data from year 1994-2010. I am only interested in data from 2008 onwards. Use the following if in statement to keep only the years that your are interested in*/
if year in (2008,2009,2010);

*weighting variables*;
/* Please define appropriate weighting variables
In Maine, prediabetes was a core question in 2008 and hence we use the weighting variable _FINALWT
In 2009 and 2010, however, it was used in only one part of the questionnaire and hence we use _FINALQ1
So you see, you can analyze years with difference weighting variables for prediabetes in one program*/
if year = 2008 then new_wt = _FINALWT;
if year = 2009 then new_wt = _FINALQ1;
if year = 2010 then new_wt = _FINALQ1;

/*Since we are combining three years of data, the final weighting variable needs to be divided by three*/
newfinalwt=new_wt/3;
newyear = year;

/*creating a dummy variable for total*/
tot=1;
format tot totf.;
run;
***ARRAY HERE*****;
/*The good part about the BRFSS is that many variables have same numbers for refused and don't know; generally it is 9, 99 or 999, or 7, 77, or 777. By creating an array as shown below you can change many variables 'missing, refused, and don't know values to "." with much ease*/

\begin{verbatim}
data d1;
set d;
*changing refused and don't know to missing;
array m                                                 
   _EDUCAG _AGEG_ _INCOMG _RACEG2
   prediab1;
do over m;
   if m =9 then m=.R;
   IF m=7 THEN m=.D;
end;
array n _INCOMG;
do over n;
   if n=99 then n=.R;
   IF n=77 THEN n=.D;
end;
*changing prediabetes during pregnancy to no prediabetes, 1= yes 2=no;
   if prediab1=. then new_prediab=.;
   else if prediab1=1 then new_prediab=1;
   else if prediab1=2 or prediab1=3 then new_prediab=2;
run;
/*And now analyze :) Because we use macros and you already specified the values above you do not need to make any changes here.
   We will NOT sort data by year as we are trying to get 3 year average.*/
proc surveyfreq data= d1;
table tot*&byvar.
   SEX* &byvar.
   _RACEG2*&byvar.
   _AGEG_*&byvar.
   _EDUCAG*&byvar.
   _INCOMG*&byvar.
/*In addition to demographic variables you can also add risk factors here like:
cholesterol* &byvar. etc.*/
/row cl ;
*output results to a data set;
ods output CrossTabs =Testtab;
strata &stratvar.;
cluster &clustvar.;
weight &weightvar.;
format _EDUCAG _EDUCAGf. _AGEG_ _AGEG_f. _INCOMG _INCOMGf.
   _RACEG2 _RACEG2f. SEX SEXf. ;
run;
*Checking data;
\end{verbatim}
/*Here we will use proc report and ods csv to create a formatted csv file*/

data tst;
set testtab;
length rowlimits $50;
if (missing(RowPercent) = 0 and RowPercent ne 100)
then rowlimits=cats((put(RowLowerCL,5.1)),"-",(put(RowUpperCL,5.1)));
if rowlimits in ('_ '-' ','_') then rowlimits='';
run;

OPTIONS LeftMargin = .5in 
RightMargin = .5in 
TopMargin = .5in 
BottomMargin = .5in;

ODS tagsets.excelxp file="&out.\Crosstabs_&byvar..xls" 
style=minimal 
options (/*contents_workbook='contents' 
contents='yes'*/ 
index='yes' 
Fittopage='yes' 
Center_Horizontal='yes' 
Pages_FitWidth = '1' 
Pages_FitHeight = '100' 
Orientation = 'landscape' 
Embedded_Titles = 'yes' 
Row_Repeat = '1-5' 
Sheet_Name="&byvar." 
Frozen_Headers = '5' 
Absolute_Column_Width='6,6,6,11,12,12,6,7,6,6,11,6,6,11,6,6,11,6,6,11,6,6,11,6,6,11,6,6,11,6,6,11,6,6,11,6,6,11,6,6,11,6,6,11,6,6,11,6,6,11,6,6,11,6,6,11');

proc report data=tst nowindows nocenter headline missing ;
column tot _EDUCAG__AGEG_ _INCOMG_ _RACEG2_ SEX 
frequency=total2 dummy &byvar., (frequency rowpercent rowlimits) ;
define tot / "Total" group center; 
define Sex / "Sex" group order=data center; 
define _INCOMG / "Income" group order=data center; 
define _AGEG_ / "Age Group" group order=data center; 
define _EDUCAG / "Education" group order=data center; 
define _RACEG2 / "Race" group order=data center; 
define &byvar. /across ORDER=Data center; 
define dummy / noprint; 
define frequency / "Counts" center; 
define rowlimits / "Percent and 95% CI" center; 
define rowpercent / "Percent" format=8.1 center; 
define total2 / "Total respondents" center; 
Title "Indicator &byvar. by Demographic Characteristics, Maine BRFSS 2010";
run;
ODS TAGSETS.EXCELPX CLOSE;
This second example calculates prevalence rates on selected variables by year and sex, using data from the Behavioral Risk Factor Surveillance System (BRFSS) for 1994 through 2010.

*The following SAS program was written by Nisha Kini, Alison Green-Parsons, and Santosh Nazare. Edits were made by Pratik Pandya and Carrie Daniels.*

/*Set libname to reference the folder where you have the dataset*/
libname BRFSS "M:\2010 Data and Information";

/*We will be using SAS macros in this program. Specify your byvariable here. I am trying to look at prediabetes rates and hence my byvariable is prediabetes. Please use the appropriate byvariable here*/
%let byvar=new_prediab;

/*We use survey data and SAS proc survey procedures to calculate rates. Please use the appropriate weighing variable here. Weighing variable will depend on whether the question is a core question and whether or not your state uses a split survey sample. Please look at your state BRFSS documentation for defining weighing variables*/
%let weightvar=newfinalwt;

*Please assign strata variable (same instructions as weighing variable);
%let stratvar=_ststr;

*Please assign cluster variable (same instructions as weighing variable);
%let clustvar=_psu;

*Please give the path(windows directory) for output files;
%let out=S:\-------\Nisha\Diabetes Surveillance Report\SAS\Prediabetes\;

data MEBRFSS;
set BRFSS.me9410_s8;

/* We are using the multiyear BRFSS dataset here which is huge and take a long time to process. Solution: Use "keep" statement to keep only the variables that you are interested in. Note: Do not forget to include the year, (part if you have split sample), weight, strata and cluster variables in the keep statement. The prediabetes variable for all years has been named PREDIAB in this dataset.*/
keep SEX PREDIAB year _finalwt _finalq1 newfinalwt _psu _ststr;

/*The input dataset contains BRFSS data from year 1994-2010. I am only interested in data from 2008 onwards.*/
Use the following if in statement to keep only the years that you're interested in:
if year in (2008, 2009, 2010);

/* Please define appropriate weighting variables
In Maine, prediabetes was a core question in 2008 and hence we use the weighting variable _FINALWT
In 2009 and 2010, however, it was used in only one part of the questionnaire and hence we use _FINALQ1
So you see, you can analyze years with difference weighting variables for prediabetes in one program*/
if year = 2008 then newfinalwt = _FINALWT;
if year = 2009 then newfinalwt = _FINALQ1;
if year = 2010 then newfinalwt = _FINALQ1;
newyear = year;
run;
proc format;
/*Use proc format to format your variables. By formatting your variables you will not have a bunch of 0,1,2s in your output which can be difficult to read and in this way you will reduce misinterpretation*/
value Sexf
  1 = "Male"
  2 = "Female";
/*creating a dummy variable for total*/
value totf
  1 = "All";
run;
data d;
set mebrfss;
tot=1;
format tot totf.;
run;
***ARRAY HERE*****;
/*The good part about the BRFSS is that many variables have same numbers for refused and don't know; generally it is 9, 99 or 999, or 7, 77, or 777. By creating an array as shown below you can change many variables's missing and refused values to "." with much ease*/
data d;
set d;
*changing refused to missing;
array m [1] PREDIAB /*add other variables here if needed*/;
do over m;
if m = 9 then m = .R /*by using .R and .D you can differentiate between refused and don't know if needed*/;
IF m = 7 THEN m = .D;
end;

* changing prediabetes during pregnancy to no prediabetes, 1 = yes 2 = no;
if PREDIAB = . then new_prediab = .;
else if PREDIAB = 1 then new_prediab = 1;
else if PREDIAB = 2 or prediab = 3 then new_prediab = 2;
run;

* THEN ADD CROSS-TABS BY YEAR **;
/* you will need to sort your data by year if you want to conduct trend analyses by year. */
Proc sort data = d;
by year;
run;

/* And now analyze :) }
Because we use macros and you already specified the values above you do not need to make any changes here*/
proc surveyfreq data = d;
table year * &byvar.
   year * SEX * &byvar.
   tot * SEX * &byvar./row cl ;

* output results to a csv file in the path you specified in the out statement;
ods csvall file="&out.&byvar.Year.csv";
strata &stratvar.;
ccluster &clustvar.;
weight &weightvar.;
run;
ods csvall close;
This third example shows a SAS program that runs three regression models where the first model has physical health as the dependent variable in the model, mental health is the dependent variable in the second model, and poor health is the dependent variable (outcome of interest) in the third model. Each model has the same independent variables or explanatory variables, which include smoking, age, sex, income, education, marital status, race and other variables. It sets the reference group for the explanatory variables. Again, it uses data from the BRFSS.

*Regression analysis for an outcome variable that is continuous or ranked data;

\%
macro reg1 (v=,);
proc regress data=brfss2010 filetype=sas design=WR;
nest _STSTR _PSU /missunit;
weight _FINALWT;
class smoke_3 aget sex income_R ed marital_1 raceT emptara HLTHPLAN_r PERSDOC2_R _TOTINDA_R chronic_3 ;
REFLEVEL smoke_3=3 aget=1 sex=1 income_R=1 ed=1 marital_1=1 raceT=1 emptara=1;
HLTHPLAN_r=1 PERSDOC2_R=1 _TOTINDA_R=1 chronic_3=3;
subpopn _state<60;
model &v= aget smoke_3 sex income_R ed marital_1 raceT emptara HLTHPLAN_r PERSDOC2_R MEDCOST_r checkup1_R fluvac _TOTINDA_R chronic_3 ;
effects aget smoke_3 / NAME = "main effects age and smoking" ;
lsmeans aget smoke_3;
Title "main effects age and smoking; state<60";
run;
%mend;
%
reg1 (v=PHYSHLTH_1);
reg1 (v=MENTHLTH_1);
reg1 (v=POORHLTH_1);

This example is similar to the one above, only because the outcome or dependent variable is a dummy variable (having only two outcomes, like yes/no), the regression is a log linear regression model.

*Log linear regression for dummy outcome variable;

proc loglink data=brfss2010 filetype=sas design=WR ;
nest _STSTR _PSU /missunit;
weight _FINALWT;
class smoke_3 aget sex income_R ed marital_1 raceT HLTHPLAN_r PERSDOC2_R MEDCOST_r checkup1_R fluvac _TOTINDA_R chronic_3;
REFLEVEL smoke_3=3 aget=1 sex=1 income_R=1 ed=1 marital_1=1 raceT=1;
HLTHPLAN_r=0 PERSDOC2_R=0 MEDCOST_r=0 checkup1_R=0 fluvac=0 _TOTINDA_R=0 chronic_3=3;
subpopn _state<60;
model MENTHLTH_2=smoke_3*aget income_R ed marital_1 raceT HLTHPLAN_r PERSDOC2_R MEDCOST_r checkup1_R fluvac _TOTINDA_R chronic_3;
effects smoke_3*aget / NAME = "1-CHUNK TEST-smoking status" ;
PREDMARG smoke_3*aget;
condMARG smoke_3*aget;
print /style=NCHS; Title "US adults state<60";
This fifth example provides useful SAS statements for labeling values of the BRFSS variables and for creating new variables of grouped results, such as a provisional depressive disorder diagnosis.

```sas
***some variable coding;

libname us06 'p:\brfss\2006\us\data\';
/*proc contents data=us06.spcl2006 varnum;
run; */
/*ADPLEASR Num 4        DAYS HAD LITTLE PLEASURE DOING THINGS
ADDOWN Num 4        DAYS FELT DOWN, DEPRESSED OR HOPELESS
ADENERGY Num 4        DAYS WERE TIRED OR HAD LITTLE ENERGY
ADEAT Num 4        DAYS ATE TOO LITTLE OR TOO MUCH
ADFAIL Num 4        DAYS FELT LIKE FAILURE OR LET FAMILY DOWN
ADTHINK Num 4        DAYS HAD TROUBLE CONCENTRATING
ADMOVE Num 4        DAYS TALKED TO MOVE SLOWER OR FASTER THAN USUAL
ADANXEV Num 4      EVER TOLD YOU HAD AN ANXIETY DISORDER
ADDEPEV Num 4       EVER TOLD YOU HAD A DEPRESSIVE DISORDER ; */

*proc freq data=us06.spcl2006 ;
*(where = (adpleasr not in (.)));
*tables _state/list missing;
*run;
*********************************
**  CONVERSION OF eight questions (PHQ-8) into ;
*************  PHQ-8 Depression Severity Index;
proc format;
   value wgt 1='obese'
            2='overweight'
            3='normal/under';

VALUE STATES
01='AL'
02='AK'
04='AZ'
05='AR'
06='CA'
08='CO'
09='CT'
10='DE'
11='DC'
12='FL'
13='GA'
15='HI'
16='ID'
17='IL'
18='IN'
19='IA'
20='KS'
```

VALUE YNFM'T
   1 = 'YES'
   2 = 'NO'
   7, 9 = 'UNKNOWN/REFUSED';

VALUE AGE7CAT
   18-24 = '18-24'
   25-34 = '25-34'
   35-44 = '35-44'
   45-54 = '45-54'
   55-64 = '55-64'
   65-74 = '65-74'
   75-99 = '75+';

VALUE SEXFM'T
   1 = 'MALE'
   2 = 'FEMALE';
VALUE RACE5FMT
   1 = 'WHITE'
   2 = 'BLACK'
   3 = 'HISPANIC'
   4 = 'OTHER'
   5 = 'MULTIRACIAL';

VALUE EDUCA
   1,2,3 = 'Less than H.S.'
   4 = 'H.S. or G.E.D.'
   5 = 'Some post-H.S.'
   6 = 'College graduate';

VALUE INCOME
   1,2 = 'Less than $15,000'
   3,4 = '$15,000 - 24,999'
   5 = '$25,000 - 34,999'
   6 = '$35,000 - 49,999'
   7,8 = '$50,000+';

VALUE MARITAL
   1 = "Married"
   2 = "Divorced"
   3 = "Widowed"
   4 = "Separated"
   5 = "Never married"
   6 = "A member of an unmarried couple"

value advars
   1,88 = 'NOT AT ALL'
   2-6 = 'SEVERAL DAYS'
   7-11 = 'MORE THAN HALF THE DAYS'
   12-14 = 'NEARLY EVERY DAY'
   77,99 = 'UNKNOWN/REFUSED';

value adindx
   0-4 = 'NONE'
   5-9 = 'MILD'
   10-14 = 'MODERATE'
   15-19 = 'MODERATELY SEVERE'
   20-24 = 'SEVERE';

value depress
   1='none'
   2='mild'
   3='moderate'
   4='moderately severe'
   5='severe';

run;

data tmpa; set us06.spcl2006
   (where = (_state in (1,2,5,6,10,11,12,13,15,18,19,
   22,23,26,27,28,29,30,32,33,35,38,40,41,72,44,45,47,
data tmpb; set us06.spc106v1 (where=(_state in (9,24,31,53))); if qstver=1; finwgt=_finalq1; run;
data tmpc; set us06.spc106v2 (where=(_state=20)); if qstver=2; finwgt=_finalq2; run;
data total; set tmpa tmpb tmpc;
if finwgt ne .; run;
%include '\cdc\private\L304\fda9\brfss\phq\format06.sas';
proc format;
value depress
  1='none'
  2='mild'
  3='moderate'
  4='moderately severe'
  5='severe';
value majdep
  1='major depression'
  2='minor depression'
  3='no depression';
value depreq
  1='severity score >=10'
  2='severity score <10';
value smoke
  1='smoker'
  2='non-smoker';
value genhlht
  1='fair/poor'
  2='excellent, very good, good';
value support
  1='usually/always'
  2='sometimes'
  3='rarely/never';
value yesno
  1='yes'
  2='no';
value racegrt
  1='White non-Hispanic'
  2='Black non-Hispanic'
  3='Hispanic'
  4='other non-Hispanic';
value sex
  1='male'
  2='female';
data tmp1; set total;
stname=fipnamel(_State);
*%include '\cdc\private\L304\fda9\brfss\phq\formas06_r.sas';
/*DAYS HAD LITTLE PLEASURE DOING THINGS*/
IF ADPLEASR in (1,88) THEN AD1 = 0;
ELSE IF ADPLEASR in (2,3,4,5,6) THEN AD1 = 1;
ELSE IF ADPLEASR in (7,8,9,10,11) THEN AD1 = 2;
ELSE IF ADPLEASR in (12,13,14) THEN AD1 = 3;
    /*DAYS FELT DOWN, DEPRESSED OR HOPELESS;*/
IF ADDOWN in (1,88) THEN AD2 = 0;
ELSE IF ADDOWN in (2,3,4,5,6) THEN AD2 = 1;
ELSE IF ADDOWN in (7,8,9,10,11) THEN AD2 = 2;
ELSE IF ADDOWN in (12,13,14) THEN AD2 = 3;
    /*DAYS HAD TROUBLE WITH SLEEP;*/
IF ADSLEEP in (1,88) THEN AD3 = 0;
ELSE IF ADSLEEP in (2,3,4,5,6) THEN AD3 = 1;
ELSE IF ADSLEEP in (7,8,9,10,11) THEN AD3 = 2;
ELSE IF ADSLEEP in (12,13,14) THEN AD3 = 3;
    /*DAYS WERE TIRED OR HAD LITTLE ENERGY;*/
IF ADENERGY in (1,88) THEN AD4 = 0;
ELSE IF ADENERGY in (2,3,4,5,6) THEN AD4 = 1;
ELSE IF ADENERGY in (7,8,9,10,11) THEN AD4 = 2;
ELSE IF ADENERGY in (12,13,14) THEN AD4 = 3;
    /*DAYS FELT LIKE FAILURE OR LET FAMILY DOWN;*/
IF ADFAIL in (1,88) THEN AD5 = 0;
ELSE IF ADFAIL in (2,3,4,5,6) THEN AD5 = 1;
ELSE IF ADFAIL in (7,8,9,10,11) THEN AD5 = 2;
ELSE IF ADFAIL in (12,13,14) THEN AD5 = 3;
    /*DAYS HAD TROUBLE CONCENTRATING;*/
IF ADTHINK in (1,88) THEN AD7 = 0;
ELSE IF ADTHINK in (2,3,4,5,6) THEN AD7 = 1;
ELSE IF ADTHINK in (7,8,9,10,11) THEN AD7 = 2;
ELSE IF ADTHINK in (12,13,14) THEN AD7 = 3;
    /*DAYS TALKED TO MOVE SLOWER OR FASTER THAN USUAL;*/
IF ADMOVE in (1,88) THEN AD8 = 0;
ELSE IF ADMOVE in (2,3,4,5,6) THEN AD8 = 1;
ELSE IF ADMOVE in (7,8,9,10,11) THEN AD8 = 2;
ELSE IF ADMOVE in (12,13,14) THEN AD8 = 3;
    IF AD1 in (0,1,2,3) & AD2 in (0,1,2,3) & AD3 in (0,1,2,3) & AD4 in (0,1,2,3) &
    AD5 in (0,1,2,3) & AD6 in (0,1,2,3) & AD7 in (0,1,2,3) & AD8 in (0,1,2,3)
THEN ADINDEX = AD1 + AD2 + AD3 + AD4 + AD5 + AD6 + AD7 + AD8;
    /*EVER TOLD YOU HAD AN ANXIETY DISORDER;*/
*ADANXEV /*EVER TOLD YOU HAD A DEPRESSIVE DISORDER;*/
array s ADPLEASR ADDOWN ADSLEEP ADENERGY ADEAT ADFAIL ADTHINK ADMOVE;
do over s;
    if s in (77,99) then depmiss=1;
end;
    if 0<=adindex<=4 then depress=1;
    if 5<=adindex<=9 then depress=2;
    if 10<=adindex<=14 then depress=3;
    if 15<=adindex<=19 then depress=4;
    if adindex>=20 then depress=5;
severity score GE 10;

if depress in (1,2) then depsub=2;
else if depress in (3,4,5) then depsub=1;
if depmiss=1 then depsub=3;

*calculating provisional depressive disorder diagnosis;

IF AD1 in (0,1,2,3) & AD2 in (0,1,2,3) & AD3 in (0,1,2,3) & AD4 in (0,1,2,3) & AD5 in (0,1,2,3) & AD6 in (0,1,2,3) & AD7 in (0,1,2,3) & AD8 in (0,1,2,3) then do;
if ad1 in (2,3) or ad2 in (2,3) then first=1;
else first=2;
if ad1 in (2,3) then ad1p=1;
else ad1p=0;
if ad2 in (2,3) then ad2p=1;
else ad2p=0;
if ad3 in (2,3) then ad3p=1;
else ad3p=0;
if ad4 in (2,3) then ad4p=1;
else ad4p=0;
if ad5 in (2,3) then ad5p=1;
else ad5p=0;
if ad6 in (2,3) then ad6p=1;
else ad6p=0;
if ad7 in (2,3) then ad7p=1;
else ad7p=0;
if ad8 in (2,3) then ad8p=1;
else ad8p=0;
totsym=ad1p+ad2p+ad3p+ad4p+ad5p+ad6p+ad7p+ad8p;
end;
if first=1 and 5<=totsym<=8 then majdep=1;
if first=1 and 2<=totsym<=4 then majdep=2;
if first=2 or 0<=totsym<2 then majdep=3;

*smoking status;

if _smoker3 in (1,2) then smokest=1;
if _smoker3 in (3,4) then smokest=2;
***********************************************************
*general health;
***********************************************************
if genhlth in (4,5) then genhlth2=1;
if genhlth in (1,2,3) then genhlth2=2;
* 7 9 refused or do not know;

***********************************************************
*Asthma status;
***********************************************************
if asthma2=1 and asthnow=1 then currasth=1;
if (asthma2=1 and asthnow=2) or asthma2=2 then currasth=2;
*lifetime diagnosis for Asthma status;

If asthma2=1 then asthma=1;
else If asthma2 in (2) then asthma=2;
label asthma=" 1 astham 2 no ";

***********************************************************
*emotional support;
***********************************************************
if emtsuprt in (1,2) then supportt=1;
if emtsuprt=3 then supportt=2;
if emtsuprt in (4,5) then supportt=3;

****************************************************************
subset by state
****************************************************************
if _state=13;

****************************************************************
*labels;
****************************************************************
label currasth='currently have asthma?'
genhlth2='general health status'
smokest='smoking status'
supportt='level of social support'
depsub='severity score GE 10?';
*if addepev ne . ;
if race2=1 then racegrt=1;
else if race2=2 then racegrt=2;
else if race2=8 then racegrt=3;
else if race2 in (3,4,5,6,7) then racegrt=4;

*health quality of life;
array qoldays physhlth menthlth poorhlth;
do over qoldays;
select;
when (qoldays eq 88) qoldays=0;
when ((qoldays lt 0) or (qoldays gt 30)) qoldays=.;
otherwise;
end;
end;
if ((physhlth eq 0) and
(menthlth eq 0) and
(poorhlth eq .)) then poorhlth=0;
* Derived measure: Unhealthy days;
if ((physhlth ne .) and
(menthlth ne .)) and
then unhealth=min(30, sum(physhlth, menthlth));
else unhealth=.;
label unhealth="# Unhealthy days in past 30 days";
* Derived measure: Percent with frequent mental distress;
select;
when (14 <= menthlth <= 30) frqmentd=100;
when (0 <= menthlth <= 13) frqmentd=0;
otherwise frqmentd=.;
end;
label frqmentd="Percent with frequent mental distress";

*education;
if educa in (1,2,3) then education=1;
else if educa in (4) then education=2;
else if educa in (5,6) then education=3;
label education='1 <12 yr 2 high school 3 college or higher';

*employment;
if employ in (1,2) then employment=1;
else if employ in (3,4) then employment=2;
else if employ in (7) then employment=3;
else if employ in (8) then employment=4;
else if employ in (5,6) then employment=5;
lable employment='1 employ 2 unemploy 3 retired 4 unable to work 5
homemake/student';

*marital status;
if marital =1 then maritals=1;
else if marital in (2,3,4) then maritals=2;
else if marital in (5,6) then maritals=3;

* health plan coverage;
if hlthplan=1 then hlthplan2=1;
else if hlthplan=2 then hlthplan2=2;
else hlthplan2=.;

array doc_diag addepev adanxev;
array doc_diag1 dep_diag anx_diag;
do over doc_diag;
if doc_diag=1 then doc_diag1=1;
else if doc_diag=2 then doc_diag1=0;
end;
if depsub=1 then score10=1;
else if depsub=2 then score10=0;

format depress depress. majdep majdep. depsub depsub. smokest smoke.
genhlth2 genhlhtt. supportt supportt. addepev adanxev yesno.
currasth yesno.;

*smoking status;
if _smoker3 in (1,2) then smoker=1; *current smoker;
else if _smoker3 in (3) then smoker=2;*former smoker;
else if _smoker3=4 then smoker=3;*never smoker;
*else if _smoker3=9 then smoker=9;
lable smoker='1 current 2 former 3 never';

*BMI;
IF (WEIGHT2 LT 500) THEN WTKQ=WEIGHT2*0.45359237;
* CODE TO INCLUDE METRIC VALUES FOR WEIGHT2;
IF (9000 LT WEIGHT2 LT 9227) THEN WTKQ=WEIGHT2-9000;
***********************************************************************;
IF (300 LE HEIGHT3 LE 399) THEN HTMETER=((HEIGHT3-300)+36)*0.0254;
IF (400 LE HEIGHT3 LE 499) THEN HTMETER=((HEIGHT3-400)+48)*0.0254;
IF (500 LE HEIGHT3 LE 599) THEN HTMETER=((HEIGHT3-500)+60)*0.0254;
IF (600 LE HEIGHT3 LE 699) THEN HTMETER=((HEIGHT3-600)+72)*0.0254;
* CODE TO INCLUDE METRIC VALUES FOR HEIGHT3;
IF (9091 LE HEIGHT3 LE 9213) THEN HTMETER=((HEIGHT3-9000)/100);
***********************************************************************;
BMI=WTKQ/(HTMETER*HTMETER);
IF (0 LE BMI LT 18.5) THEN BMICAT=3;
IF (18.5 LE BMI LT 25) THEN BMICAT=3;
IF (25 LE BMI LT 30) THEN BMICAT=2;
IF (30 LE BMI LT 40) THEN BMICAT=1;
IF (40 LE BMI) THEN BMICAT=1;

if bmicat in (1, 2) then overweight=1; *overweight/obese;
else if bmicat in (3) then overweight=2; *not;
label overweight="1 overweight/obese 2 not";

if bmicat=1 then obesity=1; *overweight/obese;
else if bmicat in (2,3) then obesity=2; *not;
label obesity="1 yes 2 not";

*Physical activity;
if exerany2=2 then exercise=1; *physically inactive;
else if exerany2 in (1) then exercise=2; *physically active;
label exercise="1 no exercise other than job 2 yes ";

*Binge drinker;
if _rfbing4=2 then bing=1; *binge drinker;
else if _rfbing4=1 then bing=2; * not binge drinker;

*Heavy Drinker _RFDRHV3;
if _rfdrhv3=2 then drkhvy=1; *heavy drinker;
else if _rfdrhv3=1 then drkhvy=2; *not heavy drinker;

*Diabetes status;
if diabete2 in (1) then diabt=1; *diabetes
else if diabete2 in (2,3,4) then diabt=2; *not diabetes;
label diabt='1 diabetes 2 no';

*CVD status;
if cvdcrhd3 in (1,2) and cvdinfr3 in (1,2)
and cvdstrk3 in (1,2)
then do;
if cvdcrhd3=1 or cvdinfr3=1 or cvdstrk3=1 then cvd=1;
else cvd=2;
end;
*CHD;
if cvdcrhd3=1 or cvdinfr3=1 then CHD=1;
else if cvdcrhd3 ne . and cvdinfr3 ne . then chd=2;
*stroke;
if cvdstrk3=1 then stroke=1;
else if cvdstrk3 ne . then stroke=2;

dummy=1;
if physhlth in (77,99) then physical=.;
else if physhlth=88 then physical=0;
else physical=physhlth;
if physical>=3 then poorphy=1;
else if physical<3 and physical ne . then poorphy=2;
if useequip=1 or qlactlm2=1 then disability=1;
else if useequip in (2,7,9) and qlactlm2 in (2,7,9) then disability=2;
array d poorphy disability genhlth2;
array dl poorphy2 disability2 genhlth2_2;
do over d;
if d=1 then dl=1;
else if d=2 then dl=0;
end;
run;
This sixth example provides SAS statement for merging multiple years of BRFSS data and for testing if there is an age and year interaction or effect modification.

***Merging multiple years’ data;

```sas
data SDtrend01;
set DATAV6.dbrfs01 (keep=_state _finalwt _STSTR SEQNO PSU _QSTVER _racegr2 sex educa age marital employ DIABETES CVDINFR2 CVDCRHD2 CVDSTRK2 _SMOKER2 STOPSMK2);
cvdinfr4=CVDINFR2;
cvdcrhd4=CVDCRHD2;
cvdstrk3=CVDSTRK2;
_SMOKER3=_SMOKER2;
QSTVER=_QSTVER;
year=2001;
run;

data SDtrend02;
set DATAV7.dbrfs02 (keep=_state _finalwt _STSTR SEQNO PSU _QSTVER _racegr2 sex educa age marital employ DIABETES CVDINFR2 CVDCRHD2 CVDSTRK2 _SMOKER2 STOPSMK2);
cvdinfr4=CVDINFR2;
cvdcrhd4=CVDCRHD2;
cvdstrk3=CVDSTRK2;
_SMOKER3=_SMOKER2;
QSTVER=_QSTVER;
year=2002;
run;

data SDtrend03;
set DATAV7.dbrfs03 (keep=_state _finalwt _STSTR SEQNO PSU _QSTVER _racegr2 sex educa age marital employ DIABETES CVDINFR2 CVDCRHD2 CVDSTRK2 _SMOKER2 STOPSMK2);
cvdinfr4=CVDINFR2;
cvdcrhd4=CVDCRHD2;
cvdstrk3=CVDSTRK2;
_SMOKER3=_SMOKER2;
year=2003;
run;

data SDtrend04;
set DATAV7.dbrfs04 (keep=_state _finalwt _STSTR SEQNO PSU _QSTVER _racegr2 sex educa age marital employ DIABETES CVDINFR2 CVDCRHD2 CVDSTRK2 _SMOKER2 STOPSMK2);
cvdinfr4=CVDINFR2;
cvdcrhd4=CVDCRHD2;
cvdstrk3=CVDSTRK2;
_SMOKER3=_SMOKER2;
year=2004;
run;

data SDtrend05;
set DATAV7.dbrfs05 (keep=_state _finalwt _STSTR SEQNO PSU _QSTVER _racegr2 sex educa age marital employ DIABETES CVDINFR3 CVDCRHD3 CVDSTRK3 _SMOKER3 STOPSMK2);
cvdinfr4=CVDINFR3;
cvdcrhd4=CVDCRHD3;
```

year=2005;
run;
data SDtrend06;
set DATAV7.dbrfs06 (keep=_state _finalwt _STSTR SEQNO _PSU QSTVER _racegr2
sex educa age marital employ
DIABETE2 CVDINFR3 CVDCRHD3 CVDSTRK3 _SMOKER3 STOPSMK2);
cvdinfr4=CVDINFR3;
cvdcrh4=CVDCRHD3;
year=2006;
run;
data SDtrend07;
set DATAV7.dbrfs07 (keep=_state _finalwt _STSTR SEQNO _PSU QSTVER _racegr2
sex educa age marital employ
DIABETE2 CVDINFR4 CVDCRHD4 CVDSTRK3 _SMOKER3 STOPSMK2);
year=2007;
run;
data SDtrend08;
set DATAV7.dbrfs08 (keep=_state _finalwt _STSTR SEQNO _PSU QSTVER _racegr2
sex educa age marital employ
DIABETE2 CVDINFR4 CVDCRHD4 CVDSTRK3 _SMOKER3 STOPSMK2);
year=2008;
run;
data SDtrend09;
set DATAV7.dbrfs09 (keep=_state _finalwt _STSTR SEQNO _PSU QSTVER _racegr2
sex educa age marital employ
DIABETE2 CVDINFR4 CVDCRHD4 CVDSTRK3 _SMOKER3 STOPSMK2);
year=2009;
run;
data SDtrend10;
set DATAV7.dbrfs10 (keep=_state _finalwt _STSTR SEQNO _PSU QSTVER _racegr2
sex educa age marital employ
DIABETE2 CVDINFR4 CVDCRHD4 CVDSTRK3 _SMOKER3 STOPSMK2);
year=2010;
run;
data total;
set SDtrend01 SDtrend02 SDtrend03 SDtrend04
SDtrend05 SDtrend06 SDtrend07 SDtrend08 SDtrend09 sdtrend10;
run;
*test whether there is age*year interaction;
PROC CROSSTAB DESIGN=WR FILETYPE=SAS DATA =dataamy.total0110;
NEST year _ststr _PSU /psulev=3 MISSUNIT;
WEIGHT _FINALWT;
CLASS year racet aget sex ed;
SUBPOPN diab=1;*SUBPOPN diab=2;
TABLES year*aget;
test chisq llchisq;
run;
PROC REGRESS data=dataamy.total0110 filetype=sas design=WR;
NEST year _STSTR _PSU /missunit;
WEIGHT _FINALWT;
CLASS year;
SUBPOPN diab=1;
model age=year;
EFFECTS year / NAME = "1-CHUNK TEST-year";
lsmeans year;
run;

PROC descript DESIGN=WR FILETYPE=SAS DATA =dataamy.total0110;
NEST year _ststr _PSU /psulev=3 MISSUNIT;
WEIGHT _FINALWT;
var smoke ;
catlevel 1;
class year diab sex;
tables year*diab*sex;
PRINT NSUM PERCENT SEPERCENT LOWPCT UPPCT/ STYLE=NCHS;
title "Table 1. current cigarette smoking among adults aged >18 years by 
diabetes status 2001 to 2009";
run;

This seventh SAS example runs several regression analyses where the basic model has smoking status as the dependent variable and diabetes, year, and an interaction term for diabetes and year as independent variables. Additional demographics enter the basic model as independent variables.

*smoking prevalence trend analysis by diabetes and demographic group;

%macro regress1(va=);
proc regress data=dataamy.total0110 filetype=sas design=WR;
nest year _STSTR _PSU /psulev=3 missunit;
weight _FINALWT;
model smoker=year diab year*diab;
class diab &va;
rby &va;
print beta sebeta t_beta P_beta/style=NCHS betaFMT = I0.8 SEbetaFMT = I0.8;
run;
%mend;
%regress1(va=aget);
%regress1(va=sex);*2;
%regress1(va=ed);*3;
%regress1(va=racet);*4;
%regress1(va=martar);*3;

This eighth SAS program runs a trend analysis for quit attempts among non-diabetic smokers.

*trend analysis for quit attempt;

PROC descript DESIGN=WR FILETYPE=SAS DATA =dataamy.total0109;
NEST year _ststr _PSU /psulev=3 MISSUNIT;
WEIGHT _FINALWT;
subpopn smoke=1 and diab=2; *non-diabetic current smoker;
var stopsmk2;
catlevel 1;
class year ;
poly year=3;
title "stopped smoking for >=1 day for quit attempt 2000 to 2009";
run;
Appendix B: More Links to Helpful Resources

Resources and their links are listed by topic in alphabetically order.

Best Practices for Chronic Disease Epidemiology


Capacity Assessment for Epidemiology

As part of workforce development, CSTE provides surveys that can be used to assess the capacity of epidemiology in chronic disease, maternal and child health, oral health, and environmental health: http://www.cste.org/group/ECA

Disease and Procedure Codes

- Document produced by CDC’s Division of Heart Disease and Stroke Prevention containing codes the Division uses for surveillance purposes  

- ICD-10-CM codes http://www.icd10data.com/ICD10CM/Codes

Epidemiology and Evaluation Resource Guides

- NACDD’s Cardiovascular Health Council: http://www.chronicdisease.org/?page=CVHEpiEval
CDC Division for Heart Disease and Stroke Prevention
http://www.cdc.gov/dhdsp/evaluation_resources.htm and

CDC Smoking & Tobacco Use
http://www.cdc.gov/tobacco/tobacco_control_programs/surveillance_evaluation/

CDC State Asthma Program Evaluation Guide
http://www.cdc.gov/asthma/program_eval/guide.htm

Health System Strategies for Chronic Disease Prevention and Control

Meta-analysis
Cochrane Reviews Meta-analysis Program: http://ims.cochrane.org/revman/

SAS
Find a local user group and join their listserv or blog:
http://support.sas.com/usergroups/index.html
Subscribe to an e-newsletter: http://support.sas.com/community/newsletters/index.html
Ask for the government pricing on training: http://support.sas.com/learn/
Ask if you can join CDC’s SAS listserv or your department’s SAS user group and listserv

Statistics
Age-adjustment
• National Association for Public Health Statistics and Information Systems Age-adjustment Protocols:
http://www.naphsis.org/about/Documents/Mortality_AgeAdj_Final_Lois.pdf
Life Expectancy

- Statehealthfacts.org (by state and gender, 2010) [http://www.statehealthfacts.org/comparemaptable.jsp?ind=967&cat=2](http://www.statehealthfacts.org/comparemaptable.jsp?ind=967&cat=2)

Sample Size and Power Calculations

Vanderbilt University Department of Biostatistics Sample Size and Power Calculator: [http://biostat.mc.vanderbilt.edu/wiki/Main/PowerSampleSize#PS_Power_and_Sample_Size_Calculator](http://biostat.mc.vanderbilt.edu/wiki/Main/PowerSampleSize#PS_Power_and_Sample_Size_Calculator)

Surveillance Resources


GIS


Indicators and Data

- CDC Chronic Disease Indicators: [http://apps.nccd.cdc.gov/cdi/](http://apps.nccd.cdc.gov/cdi/)
- Maternal and Child Health: [https://perf-data.hrsa.gov/MCHB/TVISReports/MeasurementData/MeasurementDataMenu.aspx](https://perf-data.hrsa.gov/MCHB/TVISReports/MeasurementData/MeasurementDataMenu.aspx)
  - Life Course Indicators: [http://www.amchp.org/programsandtopics/data-assessment/Pages/LifeCourseIndicators.aspx](http://www.amchp.org/programsandtopics/data-assessment/Pages/LifeCourseIndicators.aspx)
  - Preconception Health Indicators: [http://www.cste.org/?PreconIndicators](http://www.cste.org/?PreconIndicators)
Reproductive Health data:  
http://www.cdc.gov/reproductivehealth/Data_Stats/index.htm

- National Oral Health Surveillance System:  www.cdc.gov/nohss/
- Social Determinants of Health:

  CDC Data Set Directory of Social Determinants of Health at the Local Level:  
  http://www.cdc.gov/dhdsp/docs/data_set_directory.pdf


Sample state surveillance plans
Iowa Asthma Surveillance Plan:  
https://www.idph.state.ia.us/hpcdp/common/pdf/asthma_plan_2003.pdf

North Carolina’s Physical Activity and Nutrition Surveillance Plan:  

North Dakota Oral Health Surveillance Plan:  

Rhode Island Oral Health Surveillance Plan:  

State Point of Contacts from the CSTE Web site accessed on March 9, 2014:

State Chronic Disease Epidemiology Contacts:  http://www.cste.org/?page=ChronicPOC

State Maternal and Child Health Epidemiology Contacts:  http://www.cste.org/?page=MCHPOC

Oral Health Epidemiology Contacts:  
State surveillance coordinators from the CDC Web site accessed on March 9, 2014:

State Behavioral Risk Factor Surveillance System Coordinators:
http://apps.nccd.cdc.gov/BRFSSCoordinators/coordinator.asp

State Pregnancy Risk Assessment Monitoring System Contacts:
http://www.cdc.gov/prams/StatesContacts.htm

Training Needs

Report on State Chronic Disease Epidemiologists and Evaluators Training Needs – April 2013

http://www.chronicdisease.org/?page=EECTraining
## Appendix C: Acronyms Commonly Used in Chronic Disease Epidemiology

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACA</td>
<td>Patient Protection and Affordable Care Act</td>
</tr>
<tr>
<td>ACS</td>
<td>American Cancer Society</td>
</tr>
<tr>
<td>ADA</td>
<td>American Diabetes Association or Americans with Disability Act</td>
</tr>
<tr>
<td>ACE</td>
<td>Active community environments or Adverse Childhood Experiences BRFSS module</td>
</tr>
<tr>
<td>AHA</td>
<td>American Heart Association</td>
</tr>
<tr>
<td>AHRQ</td>
<td>Agency for Healthcare Research and Quality</td>
</tr>
<tr>
<td>ALA</td>
<td>American Lung Association</td>
</tr>
<tr>
<td>APCD</td>
<td>All-Payer Claims Database</td>
</tr>
<tr>
<td>BRFSS</td>
<td>Behavioral Risk Factor Surveillance System</td>
</tr>
<tr>
<td>CDC</td>
<td>Centers for Disease Control and Prevention</td>
</tr>
<tr>
<td>CDI</td>
<td>Chronic Disease Indicators</td>
</tr>
<tr>
<td>CHF</td>
<td>Congestive heart failure</td>
</tr>
<tr>
<td>CI</td>
<td>Confidence interval</td>
</tr>
<tr>
<td>CKD</td>
<td>Chronic kidney disease</td>
</tr>
<tr>
<td>CMS</td>
<td>Centers for Medicare and Medicaid Services</td>
</tr>
<tr>
<td>CSTE</td>
<td>Council of State and Territorial Epidemiologists</td>
</tr>
<tr>
<td>CVD</td>
<td>Cardiovascular disease</td>
</tr>
<tr>
<td>CVH</td>
<td>Cardiovascular health</td>
</tr>
<tr>
<td>DALYs</td>
<td>Disability adjusted life years</td>
</tr>
<tr>
<td>Dm</td>
<td>Diabetes</td>
</tr>
<tr>
<td>DBP</td>
<td>Diastolic blood pressure</td>
</tr>
<tr>
<td>ED</td>
<td>Emergency department, known by the public as ER or emergency room</td>
</tr>
<tr>
<td>EEC</td>
<td>Epidemiology and Evaluation Committee</td>
</tr>
<tr>
<td>EHR</td>
<td>Electronic health record</td>
</tr>
<tr>
<td>EIS</td>
<td>Epidemic Intelligence Service through CDC</td>
</tr>
<tr>
<td>EMR</td>
<td>Electronic medical record</td>
</tr>
<tr>
<td>EMS</td>
<td>Emergency Medical Services</td>
</tr>
<tr>
<td>ESRD</td>
<td>End-stage renal disease</td>
</tr>
<tr>
<td>GIS</td>
<td>Geographic information system</td>
</tr>
<tr>
<td>HBP</td>
<td>High blood pressure</td>
</tr>
<tr>
<td>HDL</td>
<td>High density lipoprotein</td>
</tr>
<tr>
<td>HEDIS</td>
<td>Healthcare Effectiveness Data and Information Set (HEDIS)</td>
</tr>
<tr>
<td>HF</td>
<td>Heart failure</td>
</tr>
<tr>
<td>HIE</td>
<td>Health information exchange</td>
</tr>
<tr>
<td>HIPAA</td>
<td>Health Insurance Portability and Accountability Act</td>
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</table>

Table continued.
<table>
<thead>
<tr>
<th>Acronym</th>
<th>Meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIT</td>
<td>Health information technology</td>
</tr>
<tr>
<td>HITECH</td>
<td>Health Information Technology for Economic and Clinical Health</td>
</tr>
<tr>
<td>HP 2020</td>
<td>Healthy People 2020</td>
</tr>
<tr>
<td>HRSA</td>
<td>Health Resources and Services Administration</td>
</tr>
<tr>
<td>ICD-10-CM</td>
<td>International Classification of Diseases, Tenth Revision, Clinical Modification (for the U.S. inpatient care and outpatient care)</td>
</tr>
<tr>
<td>JNC</td>
<td>Joint National Committee on Prevention, Detection, Evaluation, and Treatment of High Blood Pressure</td>
</tr>
<tr>
<td>LDL</td>
<td>Low density lipoprotein</td>
</tr>
<tr>
<td>MCH</td>
<td>Maternal and Child Health</td>
</tr>
<tr>
<td>MI</td>
<td>Myocardial infarction</td>
</tr>
<tr>
<td>NACDD</td>
<td>National Association of Chronic Disease Directors</td>
</tr>
<tr>
<td>NCCDPHP</td>
<td>National Center for Chronic Disease Prevention and Health Promotion</td>
</tr>
<tr>
<td>NHANES</td>
<td>National Health and Nutrition Examination Survey</td>
</tr>
<tr>
<td>NHIS</td>
<td>National Health Interview Survey</td>
</tr>
<tr>
<td>NOHSS</td>
<td>National Oral Health Surveillance System</td>
</tr>
<tr>
<td>NQF</td>
<td>National Quality Forum</td>
</tr>
<tr>
<td>OR</td>
<td>Odds ratio</td>
</tr>
<tr>
<td>PRAMS</td>
<td>Pregnancy Risk Assessment Monitoring System</td>
</tr>
<tr>
<td>QA/QC</td>
<td>Quality assurance, quality control</td>
</tr>
<tr>
<td>QALE</td>
<td>Quality adjusted life expectancy</td>
</tr>
<tr>
<td>QALYs</td>
<td>Quality adjusted life years</td>
</tr>
<tr>
<td>RCT</td>
<td>Randomized controlled trial</td>
</tr>
<tr>
<td>REC</td>
<td>Regional Extension Centers</td>
</tr>
<tr>
<td>RWJ</td>
<td>Robert Wood Johnson Foundation</td>
</tr>
<tr>
<td>RR</td>
<td>Relative risk</td>
</tr>
<tr>
<td>SDoH</td>
<td>Social determinants of health</td>
</tr>
<tr>
<td>SE</td>
<td>Standard error</td>
</tr>
<tr>
<td>STEMI</td>
<td>ST-segment elevation myocardial infarction</td>
</tr>
<tr>
<td>TIA</td>
<td>Transient Ischemic Attack, known by the public as “mini-stroke”</td>
</tr>
<tr>
<td>YPLL</td>
<td>Years of potential life lost</td>
</tr>
<tr>
<td>YRBSS</td>
<td>Youth Risk Behavior Surveillance System</td>
</tr>
</tbody>
</table>
Appendix D: Position descriptions and Related Workforce Development Resources

From the National Association of Chronic Disease Directors

- NACDD job description templates (pages 7 and 8)
  
  http://www.chronicdisease.org/resource/resmgr/workforce_development/jobdescriptiontemplates.pdf?hhSearchTerms=position+and+descriptions

Workforce Development. National Association of Chronic Disease Directors.

From CDC/CSTE:

- CDC/CSTE: Sample position description—Tier 1
  

- CDC/CSTE: Sample position description—Tier 2
  

- CDC/CSTE: Sample position description—Tier 3a
  

- CDC/CSTE: Sample position description—Tier 3b
  

Alternatively, you can access the CDC/CSTE applied competencies, short summaries, sample position descriptions, and competency assessment forms at:

  Competencies for Applied Epidemiologists in Governmental Public Health Agencies (AECs). Centers for Disease Control and Prevention Web site.
  http://www.cdc.gov/appliedepicompetencies/