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

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.

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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.\(^5\) 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,\(^6\) 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.\(^7\) Chronic diseases account for 70% of all deaths, and about 75% of health spending in the United States.\(^1,8\) 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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\(^7\) 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” 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, 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)
- 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. 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.\(^\text{13}\)

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 7-2. Sources with Data on Risk Factors and Chronic Diseases across the Lifespan

<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>Youth Tobacco Survey and National Youth Tobacco Survey</td>
<td>Tobacco use, minors’ access to tobacco, secondhand smoke exposure, media exposure, quit attempts</td>
<td>Sample of students in grades 6-12 in public high schools</td>
<td>The Youth Tobacco Survey began with data collection in 2011. States can conduct the survey to learn about initiation of tobacco use, tobacco products used, media influences, and attempts to quit. The National Youth Tobacco Survey provides similar national data for 8 years during 1999-2012. <a href="http://www.cdc.gov/tobacco/data_statistics/surveys/index.htm">www.cdc.gov/tobacco/data_statistics/surveys/index.htm</a></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.\footnote{National Health Care Survey. Centers for Disease Control and Prevention Website. Available at: \url{http://www.cdc.gov/nchs/nhcs.htm} Updated January 14, 2015. Accessed on February 16, 2015.}

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: \url{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.\footnote{Public Health Grand Rounds. Electronic Health Records: What’s In it for Everyone? Centers for Disease Control and Prevention Website. Available at: \url{http://www.cdc.gov/cdcgrandrounds/archives/2011/july2011.htm} or \url{http://www.cdc.gov/cdcgrandrounds/pdf/grehrallfinal21jul2011.pdf}, Updated January 15, 2015. Accessed February 16, 2015.} 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
electronic health records.\textsuperscript{16} 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.\textsuperscript{17} 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.\textsuperscript{18}

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</td>
</tr>
</tbody>
</table>


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 | stays, emergency department visits, and ambulatory surgery care. [http://www.hcup-us.ahrq.gov/reports/methods/methods.jsp](http://www.hcup-us.ahrq.gov/reports/methods/methods.jsp)


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/TVIS Reports/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.
Numerator Data Source: State vital records.
Denominator: Number resident live births in the state in the reporting period.
Denominator Data Source: State vital records.
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.\textsuperscript{20} 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.\textsuperscript{21} In 2012, CSTE approved revised indicators for the National Oral Health Surveillance System indicators.\textsuperscript{22} 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.\textsuperscript{23}

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,


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**

**Indicator 1A:** Percentage of adults 18 years and older with a dental visit in the past year.

**Numerator:** Number adults ≥ 18 years reporting they had a dental visit in the past year.

**Data Source:** BRFSS

**Denominator:** Number adults ≥ 18 years responding to this question on the BRFSS.

**Data Source:** BRFSS

**Statistic:** Percent
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{24} 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{25} 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.26

- 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.