Health-Care Utilization as a Proxy in Disability Determination

Committee on Health Care Utilization and Adults with Disabilities

Board on Health Care Services

Health and Medicine Division

A Consensus Study Report of

The National Academies of
SCIENCES · ENGINEERING · MEDICINE

THE NATIONAL ACADEMIES PRESS 500 Fifth Street, NW Washington, DC 20001

Suggested citation: National Academies of Sciences, Engineering, and Medicine. 2018. *Health-care utilization as a proxy in disability determination*. Washington, DC: The National Academies Press. doi: https://doi.org/10.17226/24969.

The National Academies of
SCIENCES · ENGINEERING · MEDICINE

The National Academy of Sciences was established in 1863 by an Act of Congress, signed by President Lincoln, as a private nongovernment institution to advise the nation on issues related to science and technology. Members are elected by their peers for outstanding contributions to research. Dr. Marcia McNutt is president.

The National Academy of Engineering was established in 1964 under the charter of the National Academy of Sciences to bring the practices of engineering to advising the nation. Members are elected by their peers for extraordinary contributions to engineering. Dr. C. D. Mote, Jr., is president.

The National Academy of Medicine (formerly the Institute of Medicine) was established in 1970 under the charter of the National Academy of Sciences to advise the nation on medical and health issues. Members are elected by their peers for distinguished contributions to medicine and health. Dr. Victor J. Dzau is president.

The three Academies work together as the **National Academies of Sciences, Engineering, and Medicine** to provide independent, objective analysis and advice to the nation and conduct other activities to solve complex problems and inform public-policy decisions. The National Academies also encourage education and research, recognize outstanding contributions to knowledge, and increase public understanding in matters of science, engineering, and medicine.

Learn more about the National Academies of Sciences, Engineering, and Medicine at **www.nationalacademies.org**.

The National Academies of
SCIENCES · ENGINEERING · MEDICINE

Consensus Study Reports published by the National Academies of Sciences, Engineering, and Medicine document the evidence-based consensus on studies' statements of task by committees of experts. Reports typically include findings, conclusions, and recommendations based on information gathered by the committees and the committees' deliberations. Each report has been subjected to a rigorous and independent peer-review process and represents the position of the National Academies on its statement of task.

Proceedings published by the National Academies of Sciences, Engineering, and Medicine chronicle the presentations and discussions at workshops, symposia, or other events convened by the National Academies. The statements and opinions contained in proceedings are those of the participants and are not endorsed by other participants, the planning committee, or the National Academies.

For information about other products and activities of the National Academies, please visit www.nationalacademies.org/about/whatwedo.

COMMITTEE ON HEALTH CARE UTILIZATION AND ADULTS WITH DISABILITIES

DAN G. BLAZER (*Chair*), J.P. Gibbons Professor of Psychiatry Emeritus, Duke University Medical Center
JEFF BAZARIAN, Professor of Emergency Medicine, University of Rochester
JENNIFER BOGNER, Professor, Department of Physical Medicine and Rehabilitation, The Ohio State University, Wexner Medical Center
ANNETTE L. FITZPATRICK, Research Professor and Associate Dean for Academic Services, University of Washington School of Public Health
TRACIE C. HARRISON, Professor and Director, Center for Excellence in Long Term Care, School of Nursing, The University of Texas at Austin
PHILIP D. HARVEY, Leonard M. Miller Professor of Psychiatry, University of Miami Miller School of Medicine
MIGUEL HERNAN, Kolokotrones Professor of Biostatistics and Epidemiology, Harvard T.H. Chan School of Public Health, Harvard University
RENEE Y. HSIA, Professor and Director of Health Policy Studies, Zuckerberg San Francisco General Hospital and Trauma Center, University of California, San Francisco
NICOLE MAESTAS, Associate Professor of Health Care Policy, Harvard Medical School
JUDITH McKENZIE, Professor and Division Chief, Division of Occupational Medicine, University of Pennsylvania
KATHLEEN J. MULLEN, Senior Economist and Director, RAND Center for Disability Research, RAND Corporation
LINDA ANH NGUYEN, Clinical Associate Professor of Medicine, Director, Gastrointestinal Motility and Neurogastroenterology, Stanford Medical Center
ALBERT J. OSBAHR III, Medical Director, Corporate Health Services, Spartanburg Regional Healthcare System
KEVIN A. SCHULMAN, Professor of Medicine, Duke University
SETH SEABURY, Director, Keck-Schaeffer Initiative for Population Health, University of Southern California
DONALD H. TAYLOR, JR., Professor, Sanford School of Public Policy, Duke University

Consultants to the Committee

AMY BERNSTEIN, Independent Consultant
NORMAN GROSSBLATT, Editor
NANETTE K. WENGER, Professor of Medicine (Cardiology) Emeritus, Emory University School of Medicine

Study Staff

CAROLYN FULCO, Scholar
BERNICE CHU, Associate Program Officer
JOSEPH GOODMAN, Senior Program Assistant
SHARYL NASS, Director, Board on Health Care Services

Reviewers

This consensus study report was reviewed in draft form by persons chosen for their diverse perspectives and technical expertise. The purpose of this independent review is to provide candid and critical comments that will assist the National Academies of Sciences, Engineering, and Medicine in making each published report as sound as possible and to ensure that it meets institutional standards of quality, objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the deliberative process.

We thank the following for their review of this report:

ANDREA L. CHEVILLE, Mayo Clinic
NICOLAAS E. DEUTZ, Texas A&M University
JOHN H. EXTON, Vanderbilt University School of Medicine
JODY SCHIMMEL HYDE, Mathematica Policy Research
ELLEN R. MEARA, The Dartmouth Institute for Health Policy & Clinical Practice
VINCENT MOR, Brown University
SHARON-LISE T. NORMAND, Harvard Medical School
HAROLD POLLACK, The University of Chicago
MICHELLE PUTNAM, Simmons College
CAROL A. ROMANO, Uniformed Services University of the Health Sciences
GEORGE TRIADAFILOPOULOS, Stanford University

Although the reviewers listed above provided many constructive comments and suggestions, they were not asked to endorse the conclusions or recommendations of this report, nor did they see the final draft before its release. The review of the report was overseen by **ELAINE L. LARSON,** Columbia University, and **KENNETH I. SHINE,** Dell Medical School of The University of Texas. They were responsible for making certain that an independent examination of this report was carried out in accordance with the standards of the National Academies and that all review comments were carefully considered. Responsibility for the final content rests entirely with the authoring committee and the National Academies.

Contents

5 PROXIES FOR DETERMINING LISTING-LEVEL SEVERITY   89

APPENDIXES

Acronyms and Abbreviations

ACA	Patient Protection and Affordable Care Act
ADA	Americans with Disabilities Act of 1990
ADL	activity of daily living
AF	atrial fibrillation
AHRQ	Agency for Healthcare Research and Quality
AMA	American Medical Association
ANPRM	Advance Notice of Proposed Rulemaking
APCD	All-Payer Claims Databases
ARRA	American Recovery and Reinvestment Act
ASL	American Sign Language
BMI	body mass index
BNP	brain natriuretic peptide
CDC	Centers for Disease Control and Prevention
CFR	Code of Federal Regulations
CHD	coronary heart disease
CHF	congestive heart failure
CKD	chronic kidney disease
CMS	Centers for Medicare & Medicaid Services
COBRA	Consolidated Omnibus Budget Reconciliation Act of 1985
COPD	chronic obstructive pulmonary disease
CVD	cardiovascular disease
DOD	US Department of Defense
EAP	Employee Assistance Program
ED	emergency department
EDSS	Expanded Disability Status Scale
EMR	electronic medical record
EMS	emergency medical services
EMTALA	Emergency Medical Treatment and Labor Act
FEV	Forced Expiratory Volume
FIM	functional independence measure
FMLA	Family and Medical Leave Act of 1993
FY	fiscal year
GCS	Glasgow Coma Scale
GERD	gastroesophageal reflux disease
GI	gastrointestinal

HCBS	home- and community-based services
HCUP	Healthcare Cost and Utilization Project
HDHP	high deductible health plan
HF	heart failure
HHS	US Department of Health and Human Services
HITECH	Health Information Technology for Economic and Clinical Health Act
HSA	health savings account
IBD	inflammatory bowel disease
ICD	*International Classification of Diseases*
IHD	ischemic heart disease
IHS	Indian Health Service
IOM	Institute of Medicine
KCCQ	Kansas City Cardiomyopathy Questionnaire
KFF	Kaiser Family Foundation
Listings	Social Security Listing of Impairments
LTSS	long-term services and supports
MEPS	Medical Expenditure Panel Survey
MeSH	Medical Subject Headings
MI	myocardial infarction
NAWHC	National Association of Worksite Health Centers
NCHS	National Center for Health Statistics
NCQA	National Committee for Quality Assurance
NEDS	Nationwide Emergency Department Sample
NETT	Neurological Emergencies Treatment Trials
NHIS	National Health Interview Survey
NIS	National Inpatient Sample
NPRM	Notice of Proposed Rulemaking
NRD	Nationwide Readmissions Database
OIG	Office of the Inspector General
OMB	Office of Management and Budget
PCMH	patient-centered medical home
PCP	primary care provider
PM&R	physical medicine and rehabilitation
PMADL	Performance Measure for Activity of Daily Living
POS	point of service
PPO	preferred provider organization
QDR	*National Healthcare Quality and Disparities Report*
QOL	quality of life

SASD	State Ambulatory Surgery and Services Databases
SCD	sequential compression device
SEDD	State Emergency Department Database
SEER	Surveillance, Epidemiology, and End Results
SES	socioeconomic status
SGA	substantial gainful activity
SID	state inpatient database
SLE	systemic lupus erythematosus
SNF	skilled nursing facility
SOT	statement of task
SSA	Social Security Administration
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income
TAVR	transcatheter aortic valve replacement
TBI	traumatic brain injury
TBSA	total body surface area
USCB	US Census Bureau
VA	US Department of Veterans Affairs
VHD	valvular heart disease
VTE	venous thromboembolism
WC	workers' compensation

Summary

The Social Security Administration (SSA) administers two programs that provide benefits based on disability: the Social Security Disability Insurance (SSDI) program and the Supplemental Security Income (SSI) program. The SSDI program provides disability benefits to people who are under the full retirement age and are no longer able to work because of a disabling medical condition or because they have a terminal illness. The SSI program is a means-tested income-assistance program for disabled, blind, and aged people who have limited income and resources regardless of their prior participation in the labor force. The programs have a common definition of disability in adults—"the inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months"—and a common disability-determination process administered by SSA. Disabled workers might receive either SSDI benefits, SSI payments, or both, depending on their recent work history and current income and assets. They might also receive benefits from other public programs, such as worker's compensation, which insures against work-related illness or injuries occurring on the job, but the other programs have their own definitions and eligibility criteria.[1]

In the present report, the Committee on Health Care Utilization and Adults with Disabilities discusses the SSDI and SSI programs because they both use the Listing of Impairments[2] (also referred to as the Listings) in their determination process.[3] The Listings includes hospitalization as a criterion for receiving disability insurance for health conditions of six body systems: respiratory, cardiovascular, digestive, genitourinary, hematologic, and immune. They require an applicant to have, for a particular medical condition or combination of conditions, "exacerbations or complications requiring three hospitalizations within a 12-month period and at least 30 days apart" of which "each hospitalization must last at least 48 hours, including hours in a hospital emergency department immediately before the hospitalization."

The committee sought to understand the SSA programs and disability-determination process: SSA tasked the committee with providing an analysis of health-care utilizations as they relate to impairment severity and SSA's definition of disability. The committee sought to identify types of utilizations that might be good proxies for listing-level severity, that is, what represents an impairment, or combination of impairments, severe enough to prevent a person

---

[1]There is no federal role in state worker compensation. State compensation programs vary widely with regard to coverage, benefits, and administrative practices (*Social Security Bulletin,* Volume 65, No. 4, 2004).

[2]See https://www.ssa.gov/disability/professionals/bluebook/AdultListings.htm, accessed February 1, 2018.

[3]See 20 Code of Federal Regulations (CFR) Part 404, Subpart P, Appendix 1.

from doing any gainful activity regardless of age, education, or work experience. The committee's full statement of task is provided later in this Summary.

THE LISTING OF IMPAIRMENTS

SSA has a five-step sequential process to determine whether someone is medically eligible for SSDI or SSI benefit. The third step of the sequential evaluation process relies on the Listing of Impairments[4] to identify cases that can be allowed regardless of an applicant's age, education, or work experience. The Listings are organized by 14 body systems for adults (see Table S-1) and includes for each system impairment that SSA considers severe enough to prevent an adult from performing any gainful activity. The SSA Office of the Inspector General noted in 2015 that "the Listings help ensure that disability determinations are medically sound, claimants receive equal treatment based on the specific criteria, and disabled individuals can be readily identified and awarded benefits, if appropriate." Applicants whose impairments do not meet or medically equal a Listing can still be determined to be disabled at step 5 on the basis of the combination of their residual functional capacity, age, education, and work experience.

Although an established "listing of medical impairments" has existed since the disability program began in 1956, SSA did not publish the Listings in its disability regulations until 1968.[5] Since then, it has revised the Listings periodically to reflect advances in medical knowledge. In 2003, SSA implemented a new process for revising the Listings, which was designed to ensure continuous updates and monitoring of the Listings about every 3–4 years.

TABLE S-1 Body Systems in Social Security Administration Listings for Adults

1.0   Musculoskeletal system
2.0   Special senses and speech
3.0   Respiratory disorders
4.0   Cardiovascular system
5.0   Digestive system
6.0   Genitourinary disorders
7.0   Hematologic disorders
8.0   Skin disorders
9.0   Endocrine disorders
10.0 Congenital disorders that affect multiple body systems
11.0 Neurologic disorders
12.0 Mental disorders
13.0 Cancer (malignant neoplastic diseases)
14.0 Immune system disorders

SOURCE: Disability Evaluation Under Social Security, SSA, September 2008.

---

[4]Found in 20 CFR Part 404, Subpart P, Appendix I.
[5]See https://secure.ssa.gov/poms.nsf/lnx/0434101005, accessed February 1, 2018, for an explanation of the Listing of Impairments before 1968.

Seven body systems were last updated during 2009–2015. The SSA Office of the Inspector General recommended that by the end of fiscal year (FY) 2020 SSA should ensure that all Listings updates are less than 5 years old and that SSA continue to update them as needed to reflect current medical knowledge and advances in technology. Four more body systems (respiratory, neurologic, mental, and immune-system disorders) were updated in 2016–2017.

STATEMENT OF TASK

SSA asked the National Academies of Sciences, Engineering, and Medicine to conduct a study of health-care utilizations by adults being evaluated for disability determination. The statement of task follows:

> An ad hoc committee will provide an analysis of health care utilizations as they relate to impairment severity and SSA's definition of disability. The committee will identify types of utilizations that might be good proxies for "listing-level" severity; that is, what represents an impairment, or combination of impairments, that are severe enough to prevent a person from doing any gainful activity, regardless of age, education, or work experience.
> The task order objectives for the ad hoc committee are to
> 1. Provide a general description of the health care delivery system (for example, the Affordable Care Act, move to patient-centered care, medical homes, bundled payments, and other significant changes in the delivery of care);
> 2. Identify factors that influence a person's use of health care services;
> 3. Identify health care utilizations that represent, and are a good indicator of impairment severity for the purposes of the disability program;
> 4. Explain how intervals between utilizations and duration of utilizations affect whether health care utilization is a good indicator of impairment severity;
> 5. Explain how types of utilizations are more or less probable for particular medical conditions or combinations of medical conditions;
> 6. Describe how factors such as poverty and urbanization level affect health care utilizations; and
> 7. Describe how the health care utilizations interfere with a person's ability to work.

During the committee's meetings with SSA representatives, it came to understand that the study's focus should not be on the content of the current Listing of Impairments, nor should it be a critique of SSA's evidentiary requirements. Furthermore, the committee was not tasked with examining functional outcomes or other objective performance measures. SSA does use such information when conducting assessments at steps 4 and 5 of the disability-determination process. This report, however, is focused on step 3 of the process, that is, "whether the impairment 'meets' or 'medically equals' one of the items on the Listing of Impairments." In developing the statement of task, SSA provided numbered objectives (set forth above) in an effort to provide needed guidance. SSA noted that it did not require recommendations.

THE COMMITTEE'S APPROACH TO ITS TASK

A 16-member committee was formed to address the task. Members with diverse backgrounds and expertise were appointed to focus on the different aspects of the task. The committee met five times. It sponsored two open meetings, which enabled SSA representatives and the committee members to interact directly and discuss the motivation for the study. The committee also invited people to address health-care trends and different viewpoints on the measurement of disability. The staff conducted targeted literature searches and gathered information from relevant scientific, professional, and federal sources. After review of more than 60,000 titles and abstracts, about 700 studies were selected for further review and relevance to the committee's task.

In an effort to approximate impairment severity, the committee reviewed the literature to consider to what extent and in which ways health-care utilization might reflect disease severity, disability, and ability to perform gainful activity. The committee recognized that varied access to health care potentially confounds any observed relationships, and it sought to identify predictors of health-care utilization to assist in understanding the context of the relationship between receipt of health-care services and ability to work. The committee also considered the many types of health-care utilization, the sites where they are delivered, and whether and how they might be associated with severity of impairments.

FACTORS THAT AFFECT HEALTH-CARE UTILIZATION

People use health-care services to diagnose, cure, or ameliorate disease or injury; to improve or maintain function; or even to obtain information about their health status and prognosis. In theory, health-care utilization should correlate highly with need, but some services are needed and not obtained, and others are utilized but not clearly indicated or are indicated only after other protocols are followed.

Health status and need for health care to improve or maintain health are major determinants of health-care utilization. Ideally, need should be the major determinant of health-care utilization, but other factors clearly are involved, such as the ability to access care—including whether it is available, timely and convenient, and affordable.

There are many conceptualizations of access, and the term *access* is often used to describe factors or characteristics that influence the initial contact with or use of services. Access is also a continuum: even if care is available, many factors can affect ease of access to needed care, for example, the availability of providers who will accept a person's insurance (including Medicaid), the ease in making an appointment with a given provider, the ability of a patient to pay for care (even if insured, because of cost-sharing copayments and deductibles), and how difficult it is to arrange transportation to and from health-care facilities.

Many factors affect health-care utilization independently of need. Some of the factors reflect biologic or environmental differences among population groups, such as disproportionate residence in polluted environments, access to healthful food and adequate housing, and education associated with more effective use of health care. Other differences in health-care utilization reflect differential access, such as access to health insurance coverage or to income needed to obtain services, ease of obtaining services, or discriminatory practices by providers. A few examples are discussed below.

Race and Ethnicity

Racial and ethnic disparities are found in many sectors of American life. For example, black people, people of Hispanic origin, American Indians, Pacific Islanders, and some Asian Americans are disproportionately represented in the lower socioeconomic ranks, in lower-quality schools, and in poorer-paying jobs. Those factors can result in some racial and ethnic minorities experiencing higher rates of chronic and disabling illnesses and infectious diseases and higher mortality than white Americans. Minorities have more difficulty than the majority population in locating a "usual source" of medical care, and black and Hispanic adults report greater difficulty than whites in obtaining medical care at a consistent location.

The 2016 annual *National Healthcare Quality and Disparities Report* (*QDR*) highlights continued disparities in care that are experienced by members of different racial and socioeconomic groups. The 2016 *QDR* states that disparities decreased from 2000 through 2014–2015 but that they persist, especially for poor and uninsured populations. Furthermore, although 20 percent of measures show disparities decreasing for black people and people of Hispanic origin, most disparities have not changed substantially for any racial and ethnic groups. More than half the measures show that poor and low-income households had worse care than high-income households; more than 40 percent of the measures show that middle-income households had worse care than high-income households. Nearly two-thirds of the measures show that uninsured people had worse care than privately insured people.

Spoken Language

Many Americans in racial and ethnic minorities experience language barriers and have low or no proficiency in speaking, reading, or comprehending English. In a health-care setting, those barriers can present serious challenges to both patients and providers. A systematic review of studies of language barriers in health care of Latino populations showed that access to care, quality of care, and health status all suffer as a result of language barriers. If a patient does not speak the language of his or her health-care provider, multiple adverse effects on the patient's health care might occur. For example, a patient's inability to understand a provider's diagnosis or treatment plan can lead to poor patient satisfaction, poor compliance, and underuse of services.

Patients who face language barriers are less likely than their English-speaking counterparts to have a usual source of medical care, receive fewer preventive services, and have a greater likelihood of nonadherence to medication. Of patients who have psychiatric conditions, those who encounter language barriers are more likely than others to receive a diagnosis of a severe psychopathologic condition—but are also more likely to leave the hospital against medical advice. Such patients are less likely than others to return for followup appointments after visits to an emergency department (ED), and they have higher rates of hospitalization and drug complications.

Income and Poverty

Income correlates highly with risk factors for chronic disease. People who have lower family income typically have higher rates of heart disease, stroke, diabetes, or hypertension. People in families that have income less than 200 percent of the federal poverty level are more likely to be obese and to smoke cigarettes than wealthier people. Adults who live in poverty are

also more likely to have self-reported serious psychologic distress, as measured by a series of questions about their perceived mental health.

In all racial and ethnic groups, people who are 18–64 years old and have family income below 200 percent of the poverty level were more likely than those who had higher family income to delay seeking or not to receive needed medical care because of cost in 2009–2010. During that period, the percentage who had unmet needs for medical care decreased as family income increased from below 200 percent of the poverty level to 400 percent or more of the poverty level. Needs for medical care that were unmet because of cost were equally likely in those whose family income was below the poverty level and in those whose family income was 100–199 percent of the poverty level. Adults who were living under the poverty level reported greater rates of not receiving or of delaying seeking medical care, obtaining prescription drugs, and receiving dental care because of cost than adults who were living at 400 percent of the poverty level.

Geography

Level of urbanization has been shown to be associated with health-care utilization in several ways, including correlation of residents' sociodemographic characteristics with need and risk factors and with differential access to care. Communities at different urbanization levels differ in their demographic, environmental, economic, and social characteristics. Those characteristics influence the magnitude and types of health problems that communities face. In addition, more-urban counties tend to have a greater supply of health-care providers per capita, and residents of more-rural counties often live farther from health-care resources.

People with Disabilities

Disability is a multidimensional concept. Some health conditions associated with disability result in poor health and extensive health-care needs, but others do not. The population is clinically diverse. Some have multiple chronic conditions that are stable with treatment and will persist for years; others have extreme functional limitations. Some have mostly severe, persistent behavioral-health challenges; others have conditions that are greatly exacerbated by social factors, such as lack of housing, food, and supportive relationships. The term *disability* implies that there are limitations to a person's ability to function in one or more ways, but types of impairment also differ substantially and might differ in the extent to which they limit a person's ability to function. A person who has a disability might have

- An impairment in body structure or function or in mental functioning; examples of impairments include loss of a limb, loss of vision, or memory loss.
- An activity limitation, such as difficulty in seeing, hearing, walking, or problem-solving.
- Restrictions in participation in normal daily activities, such as working, engaging in social and recreational activities, and obtaining health-care and preventive services.

Disability can be caused by or related to, for example, genetic disorders, injuries, illness, or environmental exposures. It might be temporary, progressive, or intermittent. Thus, it is difficult to generalize about the relationship between disability and health-care utilization without targeting specific causes, diseases, or conditions. However, all people who have

disabilities have the same general health-care needs as everyone else and therefore need access to mainstream health-care services.

People with disabilities use more health-care services than people who do not, in part because many have greater need for medical and health services to treat their conditions. However, people with disabilities face a number of barriers to access to health care that are specific to their individual limitations in function. These include barriers to physical access and lack of working elevators or ramps, automatic doors, hallways and doors wide enough to accommodate wheelchairs, and accessible parking; policies that discriminate against people with disabilities as opposed to policies—in place and enforced—that are designed to accommodate people with disabilities; and lack of accommodation for communication with people with disabilities, including large-print materials, sign-language interpreters, and staff willing to try to communicate with impaired patients during scheduling or other interactions.

CHANGING PATTERNS OF HEALTH INSURANCE AND HEALTH-CARE DELIVERY

In addition to examining factors that influence access to health care, the committee was tasked with providing a general description of the health-care delivery system. Although the system is in flux, the committee did its best to summarize the current state of health care.

Health care in the United States is financed by a combination of public and private insurance, employers, and individuals paying out of pocket. In 2015, 37 percent of the US population paid for health care through a public insurance program at some point during the year. The major public insurance systems are Medicare and Medicaid. In 2016, Medicare benefit payments totaled $675 billion and accounted for 15 percent of the federal budget.

The US health-care delivery system consists of an array of clinicians, hospitals and other facilities, insurance plans, and purchasers of health-care services, all operating in various configurations of groups, networks, and independent practices. The health-care delivery system historically has been organized around the concept of fee-for-service medicine. In the fee-for-service payment model, patients (or their insurers) pay physicians and hospitals for any covered services delivered on a per-unit basis, without particular regard for price, patient outcome, or quality. Provider revenues increase as more services are provided—and insured (and some uninsured) patients do not bear the full cost of the additional services—so the fee-for-service model creates incentives to increase utilization of health-care services, and this leads in many cases to overutilization of physician and hospital visits.

The Patient Protection and Affordable Care Act (ACA) was the largest federal health policy initiative since the creation of Medicare and Medicaid. It brought about structural changes in the health-care system, which included efforts to improve access to health insurance through expansion of the Medicaid program and through subsidized and lower-cost health insurance plans made available through new health insurance marketplaces (exchanges), elimination of restrictions on coverage for pre-existing conditions, elimination of lifetime caps on health-care spending, and efforts to slow growth in health-care costs through innovative payment reforms.

A major goal of the ACA was to extend health insurance coverage to 32 million uninsured people in the United States. The plan had two major components: expansion of the Medicaid program and new structures to support the individual and small-group health insurance markets. By 2015, the uninsured rate for people who were 19–64 years old was 16 percent lower

than it had ever been, and around 30 million people who would otherwise have been uncovered had coverage from private insurance and Medicaid.

The ACA eliminated the concept of categorical eligibility for Medicaid and replaced it with a standard eligibility criterion of 138 percent of the federal poverty level. In 2012, the Supreme Court ruled that the federal government could not force the states to expand Medicaid coverage. As a result, only 32 states and the District of Columbia elected to expand Medicaid. One estimate shows that around 17.5 million people would not have been covered by Medicaid had it not been for the ACA.

For the individual and small-group markets, the ACA established health insurance exchanges in states to allow individuals and small groups to buy standard insurance policies with income-based subsidies from 138 percent to 400 percent of the federal poverty level. The ACA eliminated medical underwriting and imposed a legal mandate to purchase health insurance, with a penalty for those who did not comply. Before the ACA, insurance companies used medical underwriting to determine whether to offer a person coverage, at what price, and with what exclusions or limits based on health status; the purpose was to ensure a healthy risk pool by requiring people to pay premiums that reflected their expected medical costs. Because of medical underwriting in the individual and small-group markets, people who were sick often paid higher premiums or were denied coverage. The ACA's individual mandate, in contrast, was intended to compel healthier people to purchase insurance and thereby to balance the risk pool and lower premiums for everyone.

The ACA included payment-reform provisions to incentivize the adoption of more effective care-delivery models. The new models involve some combination of risk-sharing among providers to enhance collaboration and coordination of care in an effort to reduce avoidable hospitalizations, ED visits, and other forms of expensive or unnecessary care. To protect against stinting, quality metrics are often used to evaluate provider performance. Beyond payment models, the ACA encouraged the narrowing of provider networks (perhaps unintentionally) and reshaped the delivery of long-term services and supports, all of which have implications for how people who have disabilities receive care and for the documentation of that care in the medical record.

The ACA has many provisions that are important for people who have disabilities. For example, denial of coverage because of pre-existing conditions is no longer allowed, and the expansion of health insurance coverage through the Medicaid program, the health insurance exchanges, and the dependent-coverage provision will allow many Americans who have disabilities to obtain health insurance coverage without having also to qualify for SSDI or SSI.

HEALTH-CARE UTILIZATIONS AS PROXIES
FOR LISTING-LEVEL SEVERITY

The committee's extensive literature review found no studies that addressed the usefulness of health-care utilizations in determining disability or impairment severity and few that addressed the association of health-care utilization with disability. The question of whether health-care utilizations can be proxies for disability or impairment severity according to SSA's definition has not been extensively researched in the health sciences. In the absence of such data, the committee reviewed literature that links health-care utilizations to similar concepts, such as disease severity and ability to work.

The committee found no evidence that health-care utilizations alone can predict disability, impairment severity, or disease severity. For several medical conditions, including chronic obstructive pulmonary disease (COPD) and chronic kidney disease, there is some evidence that increased hospitalizations, ED visits, and outpatient physician visits might predict disease severity for some specific diagnoses. However, their relevance to the committee's task is limited in that *disease* severity does not fit SSA's definition of *impairment* severity and statistical modeling in the supporting papers involved more factors than health-care utilization, such as individual and societal factors that influence the use of health care.

Another intervening variable is the presence of comorbid conditions. In particular, psychiatric disorders were found to increase the likelihood of disability and of the use of health-care services for medical conditions of several body systems.

With few exceptions, the health-care utilizations featured in the committee's literature review were hospitalizations, ED visits, and outpatient physician visits. Given that annual data on hospitalizations have been collected in the United States since 1965, hospital data are easy to capture and are more likely than data on other utilizations to constitute a reliable measure of impairment severity associated with some diseases. The fragmented nature of the health-care delivery system, however, makes it difficult to capture all the different types and locations of utilizations for purposes of determining disease severity.

In addition, little research has attempted to account for the relationships among employment, health, and disability. Some studies have explored effects of health on disability or vice versa but rarely in a manner that acknowledges that health problems interfere with the ability to work.

A PROXY FOR DETERMINING LISTING-LEVEL SEVERITY

Inasmuch as there is scant literature on health-care utilizations that would be good proxies for listing-level disability, the committee considered "What would make a good proxy?" Listing-level severity—defined by SSA as the inability to perform any gainful activity regardless of age, education, or work experience—is not easy to measure in practice. It has been noted, in some studies, that the disability-determination process provides applicants with a strong disincentive to work inasmuch as any (substantial) gainful activity performed during or immediately before the application period can be used as evidence that an applicant can de facto work.

Development of a classifier to improve assessments of disability would have to find a balance between false positives and false negatives. From a societal point of view, a false positive might be viewed as a more expensive mistake than a false negative. A possible strategy might be to choose classifiers that err on the side of increasing false negatives rather than false positives, that is, classifiers that have higher specificity at the expense of lower sensitivity. However, the relative emphasis on positive predictive value versus negative predictive value depends on the goals of the classification. In any case, the decision to privilege false negatives over false positives, or vice versa, is a judgment that SSA must make. The committee examined the characteristics of classifiers of listing-level severity and discusses the elements of a study that might predict utilizations that would be a proxy for listing-level severity.

CONCLUSIONS

Many factors influence the use of health care (e.g., race and ethnicity, income, and language). Those factors combine to affect the health of individuals and communities, and it is often difficult to disentangle these issues. Numerous studies have demonstrated a strong association between race, low socioeconomic status, and the lack of potential access to care (e.g., no insurance coverage and no regular source of care) and poor receipt of health-care services. Social determinants (e.g., race and ethnicity, language, income, and poverty) have a substantial effect on health-care utilization and health outcomes. Different geographic regions of the country experience different degrees of availability of health care; urban regions have easier access than rural areas. Transportation to and from health-care sites also influence utilizations.

People with disabilities face a number of barriers to access to health care that are specific to their individual limitations in function, including physical access—lack of working elevators or ramps, automatic doors, hallways and doors wide enough to accommodate wheelchairs, and accessible parking—and lack of accommodation for barriers to communication, such as staff willing to try to communicate with impaired patients during scheduling or other interactions.

There have been many changes in the health-care system, for example, movement away from hospitalizations, movement toward outpatient settings or ambulatory care centers, and discouragement of rehospitalizations; thus, utilization might be a poor marker of disease severity and disability. Furthermore, patterns of utilization can be dramatically altered by changes in insurance coverage or by legislative, executive, or state actions. The ACA has expanded coverage, especially of low-income people and more so in states that have expanded Medicaid, and there has been a substantial increase in cost-sharing in the private insurance market (including the growth of high-deductible health plans not related to the ACA) that might decrease utilization.

The committee was unable to find an association between health-care utilizations (such as inpatient hospitalizations, ED use, and hospital readmissions) and disease severity *as it relates to SSA's definition of listing-level impairment severity* (i.e., what represents an impairment or combination of impairments severe enough to prevent a person from performing any gainful activity regardless of age, education, or work experience). In some cases, health-care utilizations and repeat utilizations indicate *disease* severity, but are not necessarily under SSA's definition of *impairment* severity.

In other cases, utilizations might indicate poor health care, poverty, lack of insurance, and so on, rather than impairment severity. The scientific and medical literature reviewed did, in some cases, link utilizations (and repeat utilizations) with disease severity, but it did not (and therefore the committee could not) make the leap of connecting health-care utilizations and disease severity with SSA's definition of impairment severity.

Finally, given appropriate data—such as administrative records of past SSDI applications merged with data on health-care utilizations available at the time of determination and data on postdetermination work outcomes—there are models for quantifying the value of health-care utilizations for determining impairment severity.

1

Introduction

The Social Security Administration (SSA) administers two programs that provide disability benefits: the Social Security Disability Insurance (SSDI) program and the Supplemental Security Income (SSI) program. SSDI provides disability benefits to people (under the full retirement age) who are no longer able to work because of a disabling medical condition (or who have a terminal illness). SSI provides income assistance for disabled, blind, and aged people who have limited income and resources regardless of their prior participation in the labor force (SSA, 2017a). Both programs share a common definition of disability for adults, i.e., "the inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months," as well as a common disability determination process administered by SSA (SSA, 2017a). Disabled workers might receive either SSDI benefits or SSI payments, or both, depending on their recent work history and current income and assets. Disabled workers might also receive benefits from other public programs such as workers' compensation, which insures against work-related illness or injuries occurring on the job, but those other programs have their own definitions and eligibility criteria.[1]

In the present report, the Committee on Health Care Utilization and Adults with Disabilities (hereafter referred to as "the committee") discusses SSDI and SSI as they both employ the Listing of Impairments[2] (also referred to as "the Listings") in their determination processes.[3] This chapter introduces the two programs and discusses the disability-determination process. The remainder of the chapter presents the committee's task, its approach to the task, and the organization of the report.

THE SOCIAL SECURITY DISABILITY INSURANCE PROGRAM

The SSDI program was authorized by Title II of the Social Security Act and enacted in 1956 to provide benefits to disabled workers who have paid into the Social Security system and

---

[1]There is no federal role in state workers' compensation. State compensation programs vary widely with regard to coverage, benefits, and administrative practices (*Social Security Bulletin*, Volume 65, No. 4, 2005).
[2]See https://www.ssa.gov/disability/professionals/bluebook/AdultListings.htm, accessed February 1, 2018 (SSA, 2017b).
[3]See 20 Code of Federal Regulations (CFR) Part 404, Subpart P, Appendix 1.

who are younger than the Social Security full retirement age. The goal of SSDI is to replace a portion of a worker's income in the event of illness or disability in amounts related to the worker's former earnings. The SSDI program also provides Medicare coverage after a 2-year waiting period. SSDI is financed by the Social Security payroll tax, so any person who qualifies as disabled, according to the SSA definition of *disability* (inability to engage in any substantial gainful activity) and has paid Social Security taxes long enough to achieve sufficient work credits can receive SSDI.

In December 2016, almost 9 million people received disabled-worker benefits under the SSDI program. Some 1.8 million children and 148,955 spouses of disabled workers also received benefits. The average monthly benefit to disabled workers was $1,171, which is equivalent to $14,052 a year.[4] As noted, SSDI benefits are financed primarily through Social Security payroll-tax contributions, which totaled about $143 billion in 2016 (O'Leary et al., 2015; CBPP, 2017).

In December 2013, 48 percent of disabled-worker beneficiaries were women (SSA, 2013). According to the SSA 2010 National Beneficiary Survey (SSA, 2010), 70 percent of disabled workers are white, 23 percent are black, and 8 percent identify themselves as belonging to another racial group or to multiple groups; 12 percent of disabled workers identify themselves as Hispanic. Nearly 1 million veterans of the armed forces receive SSDI benefits.

About one-third of disabled-worker beneficiaries have musculoskeletal conditions (such as severe arthritis or back injuries) as a primary diagnosis. Another one-third has a diagnosis of a mental disorder. Others have life-threatening conditions, such as stage 4 cancer, leukemia, end-stage renal disease, or amyotrophic lateral sclerosis (SSA, 2016). According to O'Leary et al. (2015), one-fifth of men and one-sixth of women who enter the program die within 5 years of entry. In 2015, 0.4 percent of workers' SSDI benefits were terminated because of successful return to work (SSA, 2016).

The Social Security Supplemental Security Income Program

The SSI program, authorized by Title XVI of the Social Security Act and enacted in 1972, is a nationwide federal assistance program administered by SSA. It is funded through general revenues, and in addition to establishing disability, the applicant must also meet the nonmedical eligibility income and resource requirements, which are based on need. The basic purpose of the SSI program is to ensure a minimal income to people who are aged, blind, or disabled and who have limited income and resources. SSI recipients are also eligible to receive Medicaid coverage (without a waiting period as is the case with SSDI and Medicare coverage).[5] In 2015, 985,913 disabled workers received both SSDI and SSI benefits; among them, the average monthly SSDI benefit was $559.07, and the average monthly SSI benefit was $225.08 (SSA, 2017c).

---

[4]See https://www.ssa.gov/cgi-bin/currentpay.cgi, accessed February 1, 2018.
[5]Some states have a separate process for determining Medicaid eligibility, but all states are required to offer Medicaid to disabled SSI beneficiaries. According to SSA in "most states, if you are an SSI beneficiary, you might be automatically eligible for Medicaid; an SSI application is also an application for Medicaid. In other states, you must apply for and establish your eligibility for Medicaid with another agency. In these states, we will direct you to the office where you can apply for Medicaid" (see https://www.ssa.gov/ssi/text-other-ussi.htm, accessed March 1, 2018 [SSA, 2017c]).

THE SOCIAL SECURITY DISABILITY DETERMINATION PROCESS

SSA has a five-step sequential process (see Figure 1-1) to determine whether someone is medically eligible for SSDI or SSI benefits (see Code of Federal Regulations, 20 CFR § 404.1520).

At the first step, SSA determines whether the applicant is currently engaging in substantial gainful activity (SGA), defined as earning more than the SGA threshold, which in 2017 was set at $1,170 per month for nonblind people and $1,950 for blind people (SSA, 2017d). If the applicant is currently engaging in SGA, SSA will find that the applicant is not disabled. At the second step, the disability examiner considers the medical severity and expected duration of the applicant's impairment. If the applicant's impairment or combination of impairments is not severe or has not lasted or is unlikely to last at least 12 months, SSA will find that the applicant is not disabled. At the third step, the disability examiner determines whether the impairment "meets" or "medically equals" one of the items on the Listing of Impairments (discussed in detail in the next section). If SSA finds that the applicant's impairment meets or medically equals a listing, then SSA will find that the applicant is disabled and will receive a medical allowance.
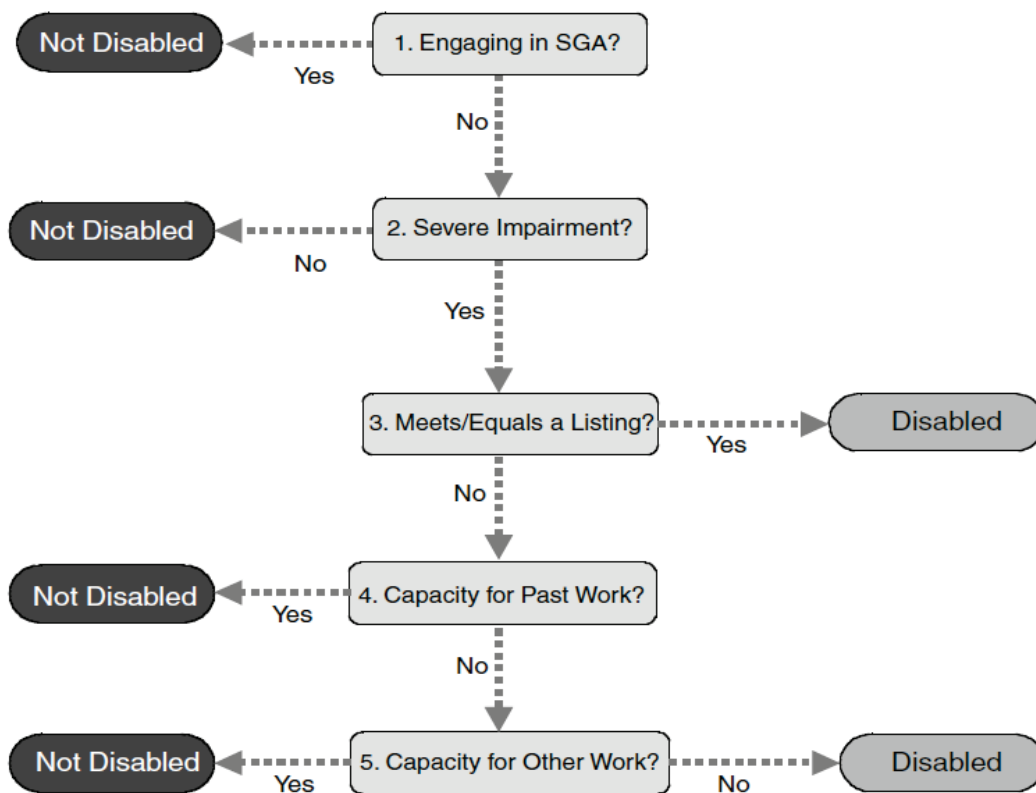

FIGURE 1-1 SSA's five-step sequential disability evaluation process.
NOTE: Substantial gainful activity (SGA) is defined as earning more than the SGA threshold, which in 2017 was set at $1,170 per month for nonblind people and $1,950 for blind people (SSA, 2017d).
SOURCE: 20 CFR § 404.1520 and 416.920.

Otherwise, the examiner moves on to the fourth step, at which point the disability examiner assesses the applicant's "residual functional capacity" (the maximum level of physical or mental performance that the applicant can achieve given the functional limitations resulting from his or her medical impairment) and determines whether the applicant is able to engage in any of his or her past relevant work; if so, the applicant will be found not to be disabled (see CFR § 404.1560(b)).

At the fifth and last step, SSA will determine whether the applicant can perform any work in the national economy on the basis of the assessment of residual functional capacity and the applicant's age, education, and work experience. If the applicant can make an adjustment to other work that exists in significant numbers in the national economy, SSA will find that the person is not disabled; otherwise, SSA will find that he or she is disabled (see CFR § 404.1560(c)). Figure 1-1 provides a visual model of the steps involved in the evaluation.[6]

Finally, it should be noted that SSA is committed to providing benefits quickly to applicants whose medical conditions are so serious that they obviously meet SSA's disability standards. SSA has two fast-track processes—Compassionate Allowances (CALs) and Quick Disability Determination (QDD)—that enable SSA to expedite review and decisions for some applications. The CAL process incorporates technology to quickly identify diseases and other medical conditions that, by definition, meet SSA's standards for disability benefits. Those conditions include certain cancers, adult brain disorders, and a number of rare disorders that affect children (SSA, 2017e). The QDD process uses a computer-based predictive model to screen initial applications and identify cases in which a favorable disability determination is highly likely and medical evidence is readily available in an effort to fast-track a (positive) determination (SSA, 2017f).

THE LISTING OF IMPAIRMENTS

The third step of the sequential evaluation process relies on the Listing of Impairments[7] (hereafter Listings) to identify cases that can be allowed regardless of the applicant's age, education, or work experience. The Listings are organized by 14 body systems for adults (see Table 1-1) and, for each system, includes impairments that SSA considers severe enough to prevent an adult from performing any gainful activity. According to the SSA Office of the Inspector General (OIG) (2015), "the Listings help ensure that disability determinations are medically sound, claimants receive equal treatment based on the specific criteria, and disabled individuals can be readily identified and awarded benefits, if appropriate." Applicants whose impairments do not meet or medically equal a Listing can still be determined disabled at step 5 on the basis of the combination of their residual functional capacity, age, education, and work experience.

---

[6]For additional details on the types of medical evidence considered in the disability-determination process and on the training and credentials required of disability examiners and medical/psychologic consultants, refer to *The Promise of Assistive Technology to Enhance Activity and Work Participation* (NASEM, 2017).
[7]Found at 20 CFR Part 404, Subpart P, Appendix I.

TABLE 1-1 Body Systems in SSA Listings for Adults

1.0 Musculoskeletal system
2.0 Special senses and speech
3.0 Respiratory disorders
4.0 Cardiovascular system
5.0 Digestive system
6.0 Genitourinary disorders
7.0 Hematological disorders
8.0 Skin disorders
9.0 Endocrine disorders
10.0 Congenital disorders that affect multiple body systems
11.0 Neurological disorders
12.0 Mental disorders
13.0 Cancer (malignant neoplastic diseases)
14.0 Immune system disorders

SOURCE: Disability Evaluation Under Social Security (SSA, 2017b).

Although there has been an established "listing of medical impairments" since the disability program began in 1956, SSA did not publish the Listings in its disability regulations until 1968.[8] Since then, it has revised the Listings periodically to reflect recent advances in medical knowledge. In 2003, SSA implemented a new process for revising the Listings, which was designed to ensure continuous updates and monitoring of the Listings about every 3–4 years (OIG, 2009). Seven body systems were last updated between 2009 and 2015. The SSA OIG recommended that by the end of fiscal year (FY) 2020, SSA should ensure that all Listings updates are less than 5 years old and that SSA continue to update them as needed to reflect current medical knowledge and advances in technology (OIG, 2015). Four more body systems (respiratory, neurologic, mental, and immune system disorders) were updated between 2016 and 2017.

After a body system is updated, SSA begins the process of identifying necessary revisions again. The process begins with information gathering within the agency (e.g., analyzing data, conducting a literature review, and obtaining feedback from adjudicators) and outside the agency (e.g., discussions with the public including medical experts and soliciting comments from the public via an Advance Notice of Proposed Rulemaking [ANPRM]. SSA develops proposed changes to the body system(s) based on its information gathering and case reviews, and drafts a Notice of Proposed Rulemaking (NPRM). The Office of Management and Budget (OMB) as well as other federal agencies (e.g., the US Departments of Health and Human Services and Veterans Affairs) review and comment on the NPRM. SSA obtains OMB approval and publishes the NPRM in the *Federal Register* for public comment. SSA reviews and responds to public comments, revises the proposed rule as needed, and drafts a final rule. OMB reviews the final rule, and SSA obtains OMB approval and publishes the final rule in the *Federal Register*.

---

[8]See https://secure.ssa.gov/poms.nsf/lnx/0434101005, accessed February 1, 2018, for an explanation of the Listing of Impairments before 1968 (SSA, 1990).

STATEMENT OF TASK

SSA asked the National Academies of Sciences, Engineering, and Medicine to conduct a study of health-care utilizations by adults being evaluated for disability determination. The statement of task follows:

> An ad hoc committee will provide an analysis of health care utilizations as they relate to impairment severity and SSA's definition of disability. The committee will identify types of utilizations that might be good proxies for "listing-level" severity; that is, what represents an impairment, or combination of impairments, that are severe enough to prevent a person from doing any gainful activity, regardless of age, education, or work experience.
>
> The task order objectives for the ad hoc committee are to

1. Provide a general description of the health care delivery system (for example, the Affordable Care Act, move to patient-centered care, medical homes, bundled payments, and other significant changes in the delivery of care);
2. Identify factors that influence a person's use of health care services;
3. Identify health care utilizations that represent, and are a good indicator of impairment severity for the purposes of the disability program;
4. Explain how intervals between utilizations and duration of utilizations affect whether health care utilization is a good indicator of impairment severity;
5. Explain how types of utilizations are more or less probable for particular medical conditions or combinations of medical conditions;
6. Describe how factors such as poverty and urbanization level affect health care utilizations; and
7. Describe how the health care utilizations interfere with a person's ability to work.

During the committee's meetings with SSA representatives, the committee came to understand that the study's focus should not be on the content of the current Listing of Impairments, nor should it be a critique of SSA's evidentiary requirements. SSA, in developing the statement of task, provided numbered objectives in an effort to provide needed guidance. SSA noted that it did not require recommendations, but the committee will present findings and conclusions. Furthermore, the committee was not tasked with examining functional outcomes or other objective performance measures. SSA does use such information when conducting assessments at steps 4 and 5 of the disability process. This report, however, is focused on step 3 of the disability process, that is, "whether the impairment 'meets' or 'medically equals' one of the items on the Listing of Impairments."

APPROACH TO THE TASK

A 16-member committee was formed to address the task. Members with diverse backgrounds and expertise were appointed to focus on the different aspects of the task. Specifically, the members have expertise in various branches of clinical medicine (psychiatry and psychology, emergency medicine, neurology, gastroenterology, occupational medicine, family medicine, and cardiology) and in biostatistics and epidemiology, nursing, rehabilitation, disability research, health-care policy, and health economics.

The committee met five times. It sponsored two open meetings, which enabled SSA representatives and the committee members to interact directly and discuss the motivation for the study. The committee also invited people to address health-care trends and different viewpoints on the measurement of disability.

The committee considered the many different types of health-care utilization and the sites where they are delivered (see Appendix A) and whether and how they might be associated with severity of impairments (see Chapter 4). In support of the committee's discussions and deliberations, the committee instructed the staff to conduct targeted literature searches, and information from relevant scientific, professional, and federal sources was gathered (see Appendix B). Staff reviewed more than 60,000 titles and abstracts; those were narrowed to about 700 studies, which the committee members carefully reviewed for relevance to the committee's task. The papers that were determined to be most relevant to the committee's task were summarized in Chapter 4 with details provided in Appendix C.

In an effort to approximate impairment severity, the committee reviewed the literature to consider to what extent and in which ways health-care utilization might reflect disease severity, disability, and ability to perform gainful activity. The committee recognized that varied access to health care potentially confounds any observed relationships, and it sought to identify predictors of health-care utilization to assist in understanding the context of the relationship between receipt of health-care services and ability to work.

Finally, the committee sought to understand both direct and indirect relationships between health-care utilization and ability to perform gainful activity. Direct relationships include the extent to which receipt of health-care services affects absenteeism and presenteeism. Indirect relationships are ones that suggest the extent to which health-care utilization can act as a proxy for severity of impairment and disability.

HEALTH-CARE UTILIZATIONS

People use health-care services for many reasons, for example, to cure or treat illnesses and health conditions, to prevent or delay future health problems, and to reduce pain and increase quality of life. Health-care utilizations might occur in traditional sites, such as hospitals, emergency departments (EDs), physician and dental offices, and nursing care facilities. However, they might also occur in less traditional sites, such as workplaces, urgent care facilities, and clinics (see Appendix A for a description of health-care utilization sites). Further, consumer preferences and new therapeutic technologies in new settings are changing how and where people obtain health care.

According to the National Center for Health Statistics (2003) the health-care delivery system has undergone many changes, even over the past decade. New and emerging technologies, such as drugs, devices, new procedures and tests, and imaging machinery, have changed patterns of care and created a shift in sites where care is provided. Improvements in anesthesia and analgesia and the development of noninvasive or minimally invasive techniques have caused a growth in ambulatory surgery. Procedures that formerly required a few weeks of convalescence now require only a few days, and new drugs can cure or lengthen the course of disease.

Health-care utilization has also evolved with changes in the population's need for care. Some influencing factors include aging, shifts in population sociodemographics, and changes in the prevalence and incidence of various diseases. For instance, as the prevalence of chronic

conditions increases, so has the presence of residential and community-based health-related services designed to minimize loss of function and keep people out of institutional settings. The growth of managed care and payment mechanisms employed by insurers and other payers to control the rate of health care spending has also impacted health-care utilization. Efforts by employers to increase managed care enrollment, as well as major Medicare and Medicaid cost containment efforts have created incentives to shift sites where services are provided (NCHS, 2003).

TRENDS IN HEALTH-CARE UTILIZATION

Over the past few decades, delivery of care has changed markedly, with a general trend of a shift from inpatient care to outpatient care. Inpatient admissions have decreased substantially: hospitalizations have decreased from 36.2 million admissions in 1975 to 34.9 million in 2014 (NCHS, 2017), a decrease of about 35 percent in the number of admissions per unit of population in four decades. In the same period, the average length of stay has decreased from 11.4 days to 6.1 days.

In contrast, utilization of outpatient care has grown greatly over the past few decades. From 1975 to 2014, the number of outpatient visits (as defined as visits to physician offices, hospital outpatient departments, and hospital EDs) more than tripled, from 254.8 million to 802.7 million, and far outpaced population growth (NCHS, 2017).

Declines in hospital use and length of stay have been attributed to cost-containment measures instituted by Medicare and Medicaid programs, other payers, employers, and to scientific and technologic advances that allowed a shift in services from hospitals to ambulatory outpatient settings, the community, home, and nursing homes (NCHS, 2003). For example, ambulatory surgery centers, facilities that perform surgeries and procedures outside the hospital, were developed to provide high-quality, cost-saving care (ASCA, 2017). Technologic and clinical advances in chemotherapies and emerging methods in radiology have resulted in the shift of cancer care from hospitals to community outpatient settings (JHC, 2017). Those shifts toward incorporation of an increasingly available health-care technology are altering how patients access the health-care system (Ticona and Schulman, 2016).

It is important to note that overall utilization rates do not indicate what services are being provided to specific people and cannot serve as proxies for access to specific services or quality of care. A physician's office visit could include tests, procedures, and even surgery, or it could consist entirely of a discussion with the physician. A hospital or nursing-home stay could be for diagnostic, palliative, or recuperative care or for medical or surgical interventions (NCHS, 2003).

Other changes in the nature of health-care utilization have been occurring. Inpatient hospitalization rates were similar in 1996 and 2006, for instance, but the prevalence of types of procedures has changed. Hospitalization rates for coronary artery stent insertions, hip replacements, and knee replacements rose sharply, and rates of some other procedures declined. Ambulatory surgery visit rates were almost twice as high in 2006 as in 1994–1996, and the increase in some types of ambulatory procedures, such as colonoscopies, was even greater (NCHS, 2010).

Health-care service use has increased in specific populations and for specific services. For example, the number of ED visits for patients who have mental health diagnoses have increased by 8.6 percent in a span of just 5 years, from 2006 to 2011 (Capp et al., 2016), and rates of visits for opioid use have risen dramatically (AHRQ, 2017). Similarly, the use of some

prescription drugs is increasing, particularly high-cost specialty and biologic drugs (Penington and Stubbings, 2016), as is multiple drug use (NCHS, 2017).

ORGANIZATION OF THE REPORT

Chapter 2 examines the numerous individual and social determinants of health-care utilization. The regional determinants of health-care utilization are also explored. Chapter 3 discusses changing patterns of health insurance and health-care delivery and their potential effects on health-care utilizations. In Chapter 4, the committee considers whether health-care utilizations might be a proxy for impairment severity, and Chapter 5 discusses the ideal characteristics of a good proxy for listing-level severity.

There are three appendixes: Appendix A describes the different sites where health-care utilizations occur; Appendix B describes the search strategy that the committee used to identify and evaluate the scientific literature used in the report; and Appendix C provides detailed summaries of the literature reviewed in Chapter 4.

REFERENCES

AHRQ (Agency for Healthcare Research and Quality). 2017. HCUP statistical brief #219: Opioid-related inpatient stays and emergency department visits by state, 2009-2014. Rockville, MD: AHRQ. https://www.hcup-us.ahrq.gov/reports/statbriefs/sb219-Opioid-Hospital-Stays-ED-Visits-by-State.jsp (accessed November 6, 2017).

ASCA (Ambulatory Surgery Center Association). 2017. *ASCs: A positive trend in health care.* http://www.ascassociation.org/advancingsurgicalcare/aboutascs/industryoverview/apositivetrendinhealthcare (accessed November 7, 2017).

Capp, R., R. Hardy, R. Lindrooth, and J. Wiler. 2016. National trends in emergency department visits by adults with mental health disorders. *The Journal of Emergency Medicine* 51(2):131–135.e131.

CBPP (Center on Budget and Policy Priorities). 2017. Chart book: Social Security disability insurance. Washington, DC: CBPP. https://www.cbpp.org/sites/default/files/atoms/files/7-21-14socsec-chartbook.pdf (accessed November 6, 2017).

JHC (*Journal of Healthcare Contracting*). 2017. Cancer care migrates to outpatient setting. *Journal of Healthcare Contracting.*

NASEM (National Academies of Sciences, Engineering, and Medicine). 2017. *The promise of assistive technology to enhance activity and work participation.* Washington, DC: The National Academies Press. https:doi.org/10.17226/24740.

NCHS (National Center for Health Statistics). 2003. *Healthcare in America: Trends in utilization.* Hyattsville, MD: US Department of Health and Human Services. https://www.cdc.gov/nchs/data/misc/healthcare.pdf (accessed March 1, 2017).

NCHS. 2010. *NCHS data brief no. 32: Health care utilization among adults aged 55–64 years: How has it changed over the past 10 years?* Hyattsville, MD: National Center for Health Statistics (US). https://www.cdc.gov/nchs/data/databriefs/db32.pdf (accessed November 8, 2017).

NCHS. 2017. Health, United States. In *Health, United States, 2016: With chartbook on long-term trends in health*. Hyattsville, MD: National Center for Health Statistics (US).

OIG (Office of the Inspector General). 2009. *The Social Security Administration's Listing of Impairments audit report a-01-08-18023.* Washington, DC: OIG. https://oig.ssa.gov/sites/default/files/audit/full/html/A-01-08-18023_7.html (accessed March 1, 2017).

OIG. 2015. *Evaluation report: The Social Security Administration's Listing of Impairments*. Washington, DC: OIG. http://oig.ssa.gov/sites/default/files/audit/full/pdf/A-01-15-50022.pdf (accessed March 1, 2017).

O'Leary, P., E. Walker, and E. Roessel. 2015. *Social Security Disability Insurance at age 60: Does it still reflect Congress' original intent?* Baltimore, MD: SSA. https://www.ssa.gov/policy/docs/issuepapers/ip2015-01.html (accessed March 1, 2017).

Penington, R., and J. A. Stubbings. 2016. Evaluation of specialty drug price trends using data from retrospective pharmacy sales transactions. *Journal of Managed Care & Specialty Pharmacy* 22(9):1010-1017.

SSA (Social Security Administration). 1990. *Di 34101.005 Listing of Impairments prior to August 1968-explanation*. Woodlawn, MD: SSA. https://secure.ssa.gov/poms.nsf/lnx/0434101005 (accessed March 1, 2017).

SSA. 2005. Social Security bulletin, vol. 65, no. 4. Woodlawn, MD: SSA. https://www.ssa.gov/policy/docs/ssb/v65n4/index.html (accessed March 1, 2017).

SSA. 2006. *Trends in the Social Security and Supplemental Security Income Disability programs*. Woodlawn, MD: SSA. https://www.ssa.gov/policy/docs/chartbooks/disability_trends/trends.pdf (accessed March 1, 2017).

SSA. 2010. *The National Beneficiary Survey (NBS)*. Woodlawn, MD: SSA. https://www.ssa.gov/disabilityresearch/nbs.html (accessed March 1, 2017).

SSA. 2013. *Fact sheet: Women who receive Social Security Disability Insurance benefits*. Woodlawn, MD: SSA. https://www.ssa.gov/news/press/factsheets/ss-customer/women-dib.pdf (accessed March 1, 2017).

SSA. 2016. *Annual statistical report on the Social Security Disability Insurance program, 2015*. Woodlawn, MD: SSA. https://www.ssa.gov/policy/docs/statcomps/di_asr/2015/di_asr15.pdf (accessed March 1, 2017).

SSA. 2017a. *Understanding Supplemental Security Income SSI income 2017 edition*. Woodlawn, MD: SSA. https://www.ssa.gov/ssi/text-income-ussi.htm (accessed March 1, 2017).

SSA. 2017b. *Disability evaluation under Social Security: Listing of impairments-adult listings (part A)*. Woodlawn, MD: SSA. https://www.ssa.gov/disability/professionals/bluebook/AdultListings.htm (accessed March 1, 2017).

SSA. 2017c. *SSI annual statistical report, 2015*. Woodlawn, MD: SSA. https://www.ssa.gov/policy/docs/statcomps/ssi_asr/2015/ssi_asr15.pdf (accessed March 1, 2017).

SSA. 2017d. *Substantial gainful activity*. https://www.ssa.gov/oact/cola/sga.html (accessed May 27, 2017).

SSA. 2017e. *Compassionate allowances*. https://www.ssa.gov/compassionateallowances (accessed March 1, 2017).

SSA. 2017f. *Quick disability determinations (QDD)*. Woodlawn, MD: SSA. https://www.ssa.gov/disabilityresearch/qdd.htm (accessed March 1, 2017).

Ticona, L., and K. A. Schulman. 2016. Extreme home makeover—the role of intensive home health care. *New England Journal of Medicine* 375(18):1707–1709.

2

Factors That Affect Health-Care Utilization

The committee was tasked with identifying factors that influence a person's use of health-care services, including poverty and level of urbanization. This chapter will address those factors. The committee has organized the beginning of the chapter around individual and societal determinants of health-care utilization, including factors that affect the need for care, the propensity to use services, and barriers to the use of services. That is followed by a brief overview of disparities in the use of health care that have differentially affected different population groups. Finally, it concludes with a discussion of what is known about the relationship between disability status and use of health-care services.

People use health-care services to diagnose, cure, or ameliorate disease or injury; to improve or maintain function; or to obtain information about their health status and prognosis. Health-care utilization can be appropriate or inappropriate, of high or low quality, and of high or low cost. Types of health-care utilizations are described in detail in Appendix A.

The health-care delivery system has undergone great change over the past few decades. New and improved drugs, devices, procedures, tests, and imaging machinery have changed patterns of care and sites where care is provided (NCHS, 2003). The growth of ambulatory surgery has been influenced by improvements in anesthesia and analgesia and by the development of noninvasive or minimally invasive techniques. New and improved, and less invasive, procedures are available to treat a number of previously untreatable conditions in a variety of new sites of care, or even in physicians' offices. New drugs can cure or lengthen the course of disease, although often at increased cost or increased utilization. Combinations of technologies can be more effective than individual ones, such as the combination of drugs now used to treat HIV/AIDS, combination chemotherapy for many types of cancers, and the recent creation of scanning machines that combine positron emission tomography and computed tomography or positron emission tomography and magnetic resonance imaging. As some technologies become easier to use and less expensive, as equipment becomes more transportable, and as recovery times for procedures are reduced, even complex technologies move out of hospitals and institutional settings and into ambulatory surgery centers, provider offices, outpatient facilities, imaging centers, and patients' homes and become more accessible. The average length of hospitalizations decreased with the diffusion of new technologies until 2010 and has been constant since then (NCHS, 2016).

The availability of newer and improved health-care services, however, does not mean that they are equally available to all Americans. For example, white women are much more likely to have outpatient surgery than women of other races or ethnicities (Salasky et al., 2014) and

Medicaid beneficiaries, who are poor and often disabled, are more likely to use emergency departments (EDs) than people who have other coverage, in part because they have less access to ambulatory care (MACPAC, 2016; NCHS, 2017a).

Health-care utilization is determined by the need for care, by whether people know that they need care, by whether they want to obtain care, and by whether care can be accessed. Quality is a construct separate from access and is related to the achievement of favorable outcomes associated with utilization, not to whether health-care utilization occurs at all or to difficulties in obtaining care. In theory, health-care utilization should correlate highly with the need, however defined, for services. But, some services are needed and not obtained, and others are utilized but not clearly indicated, or are indicated only after other protocols are followed (Kale et al., 2013; Kressin and Groeneveld, 2015; Lyu et al., 2017). The committee did not address various technologies and whether they might be useful for disability assessments, because data on technologies are insufficient for such assessments. For example, telehealth is not widely used throughout the country, and the medical field continues to try to determine how it can be used most effectively. However, the committee did examine national data when they were available.

Need for and access to health care are discussed below. Those sections are followed by a discussion of differences in utilization according to selected characteristics. Finally, health-care utilization by people who have disabilities is discussed.

NEED FOR HEALTH-CARE SERVICES

Health status and the need for health-care services to improve or maintain health are major determinants of health-care utilization. The World Health Organization states that health is determined by a person's individual characteristics and behaviors, physical environment, and socioeconomic environment (WHO, 2017). People's individual characteristics include their biology and genetics, such as inherited diseases and conditions that require medical care. The prevalence of those conditions differs by sex, age, race and ethnicity, employment status, and other factors. Physical environments can affect health because of pollutants or other environmental health hazards. Individual behaviors, such as smoking or lack of exercise and overeating, also cause health conditions that require health care (ODPHP, 2017a). Recent attention to social determinants of health, such as education, economic stability, community safety, and availability of adequate housing and healthful food, has shown that they correlate with healthier populations (ODPHP, 2017a). People who have unmet social needs are more likely to be frequent ED users, to have repeat "no-shows" for medical appointments, and to have poorer glycemic and cholesterol control than those who are able to meet their needs (Thomas-Henkel and Schulman, 2017).

How need affects differential health-care utilization by specific populations of interest is discussed below with reference to poverty and its correlates and geographic area of residence, race and ethnicity, sex, age, language spoken, and disability status. Ideally, need should be the major determinant of health-care utilization, but other factors clearly have an effect. One of those factors is the ability to access care—including whether it is available, timely and convenient, and affordable (Figueroa et al., 2017).

ACCESS TO HEALTH CARE

Access to health care is defined as having timely use of personal health services to achieve the best possible health outcome (IOM, 1993). Access requires gaining entry into the health-care system, getting access to sites of care where patients can receive needed services, and finding providers who meet the needs of patients and with whom patients can develop a relationship based on mutual communication and trust (AHRQ, 2010). Clinicians note that timely access to health care is important inasmuch as it might enable patients and physicians to prevent illness, control acute episodes, or manage chronic conditions, any of which could avoid exacerbation or complication of health conditions (NCHS, 2017b).

There are many ways to think of access, and the term *access* is often used to describe factors or characteristics that influence one's initial contact with or use of services. Anderson and Newman (2005) present a framework of health-care utilization that includes predisposing factors, enabling factors, and magnitude of illness. More recently Levesque et al. (2013) defined access to health care by presenting five dimensions of accessibility: approachability, acceptability, availability and accommodation, affordability, and appropriateness. They saw access as the opportunity to identify health-care needs; to reach, obtain, or use health-care services; and to have the need for services fulfilled. Access can be seen as a continuum: even if care is available, many factors can affect ease of access to it, for example, the availability of providers who will accept a person's insurance (including Medicaid), ease in making an appointment with a given provider, the ability of a patient to pay for care (even if a patient is insured, due to cost-sharing copayments and deductibles), and the difficulty of arranging transportation to and from health-care facilities (AHRQ, 2010, MACPAC, 2016). Some of those issues are discussed below.

Ability and Propensity to Use Services

People cannot access care if it does not exist in their geographic area, or if providers will not treat them because of insurance or other issues. Rural areas in particular have been identified as lacking a sufficient supply of specialty physicians and, in particular, mental health-care providers (Meit et al., 2014; Douthit et al., 2015).

Assuming that services are available, access to care might be impeded by other barriers. One is inadequate transportation, either because travel time is excessive, because no public transportation is available and the person does not have a car or other alternative transportation, or because the cost of transportation is prohibitive. Providers might refuse to see patients because no appointment times are open, or because they do not accept patients' insurance. Providers might be unable to communicate with patients because of language issues, or their offices might not be accessible to people with disabilities. Excessive wait times to obtain appointments or to see providers at their places of service might also deter use (MACPAC, 2016; NCHS, 2016).

Insurance and Ability to Pay for Services

Access to health care is tied to the affordability of health insurance. Financial barriers to care, particularly among low-income people and the uninsured, have been greater in the United States than in other high-income countries (Davis and Ballreich, 2014; Squires and Anderson, 2015). According to a 2013 Commonwealth Fund survey of adults in 11 high-income countries, the United States ranks last on measures of financial access to care (Schoen et al., 2013). The Kaiser Commission on Medicaid and the Uninsured notes that people who lack insurance

coverage have worse access than people who are insured, and 20 percent of uninsured adults in 2015 went without needed medical care because of cost (KFF, 2016). The lack of health insurance has been identified as an important driver of health-care disparities (IOM, 2002).

Uninsured people who are 18–64 years old are more likely than those who have Medicaid or private coverage to report difficulties in affording needed medical care and prescription drugs, and are more likely than the insured to delay or forgo them because of cost (KFF, 2016). During 2004–2014, uninsured adults were 4–5 times more likely than those who had private coverage and 1.5–3.0 times more likely than those who had Medicaid to report difficulty in medical care and prescription access. For adults who had Medicaid, medical care access problems were stable until 2008 and then decreased through 2014. For those who had private insurance, medical care access problems increased until 2009 and then decreased through 2014 (NCHS, 2016). For the uninsured, problems with medical care and prescription access increased until 2010 and 2009, respectively, and then were stable for medical care and decreased through 2014 for prescriptions. Prescription access problems were stable in 2004–2014 for those who had private insurance but decreased for adults who had Medicaid (NCHS, 2016).

Having insurance coverage does not mean that coverage is adequate or is not associated with burdensome cost-sharing through premium payments, copayments, and deductibles (Lavarreda et al., 2011; Fang et al., 2016). Surveys have categorized underinsured people as those who say they have insurance but are worried about medical bills, who are paying them off over time, or who have not obtained selected types of health-care services because of cost.

A study by Magge et al. (2013) estimated that more than one-third of low-income adults were underinsured (defined as spending more than 5 percent of household income on medical care) and that 8 percent and 13 percent deferred or delayed obtaining medical care or prescription medications, respectively (Magge et al., 2013). Avoiding or delaying medical care correlates strongly with coverage under a high-deductible health plan (in which a person must make a substantial out-of-pocket [OOP] contribution before insurance payment begins) and with depression, poor perceived health, or poverty. However, it is relatively independent of the percentage of income spent on OOP costs, so the percentage of income spent on OOP costs by itself is a poor measure of health-care unaffordability. People who spend a small percentage of their income on health care might be extremely burdened by their health-care plan when financial concerns prevent access to health care (Kielb et al., 2017). Current evidence also suggests that high-deductible health plans are associated with lower health-care costs as a result of a reduction in the use of health-care services, including appropriate services (Agarwal et al., 2017).

DIFFERENCES IN HEALTH-CARE UTILIZATION ASSOCIATED WITH SELECTED CHARACTERISTICS

Ideally, utilization of health-care services reflects a need for care, but that is not the case, for several reasons. Many factors affect health-care utilization independently of need and are reflected in differences, some of which are remediable, among population groups. Some of these factors are related to biologic or environmental differences among groups, such as disproportionate residence in polluted environments, access to healthful food and adequate housing, and education associated with effective use of health care. Others are related to differences in access, such as health insurance coverage or income needed to obtain services, ease of obtaining services, and discriminatory practices of providers.

Race and Ethnicity

Racial and ethnic disparities are found in many sectors of American life. Black people, people of Hispanic origin, American Indians, Pacific Islanders, and some Asian Americans might be disproportionately represented in the lower socioeconomic ranks, in lower-quality schools, and in poorer-paying jobs (IOM, 2002). Racial residential segregation is a key mechanism through which racism produces and perpetuates social disadvantage. Black and Latino adults are more likely to live in disadvantaged neighborhoods and to have inadequately resourced schools, which yield lower educational attainment and quality (Braveman et al., 2014). Those factors can result in some racial and ethnic minorities experiencing higher rates of chronic and disabling illnesses, infectious diseases, and higher mortality than white Americans. Minority populations have more difficulty than the majority population in locating a "usual source" of medical care, and black and Hispanic adults report greater difficulty than whites in obtaining medical care at a consistent location (IOM, 2002; AHRQ, 2010).

Black adults have earlier onset of multiple illnesses, greater severity and more rapid progression of diseases, higher levels of comorbidity and impairment throughout the life course, and higher mortality than whites up to the age of 65 years. Similar patterns are evident in American Indians, Pacific Islanders, Asian populations of low socioeconomic status, and US-born Latinos (Williams and Wyatt, 2015).

A recent report by the Kaiser Family Foundation (2016) on health and health care by race and ethnicity found that disparities in health and health care continue to pose a persistent challenge in the United States. Among their findings are the following:

- Some 41 percent of nonelderly people living in the United States are nonwhite.
- Nonwhite people[1] face substantial disparities in access to and utilization of health care.
- Black, American Indian, and Alaska Native adults fare worse than whites on most of the measures of health status and outcomes that were examined.
- Nonelderly Hispanic, black, American Indian, and Alaska Native adults remain much more likely than whites to be uninsured despite coverage gains under the ACA.

Lack of insurance, more than any other demographic or economic barrier, adversely affects the quality of health care received by minority populations (OMH, 2011). In the United States, black and Hispanic people have disproportionately lower income and higher rates of uninsurance, which might result in poorer health outcomes and different health-care utilization trends. In 2015, the percentage of people who lacked health insurance coverage for the entire calendar year was 9.1 percent or 29.0 million (USCB, 2016). Non-Hispanic whites had the lowest uninsured rate, 6.7 percent; blacks and Asian people had rates of 11.1 percent and 7.5 percent, respectively; and people of Hispanic origin had the highest rate, 16.2 percent. From 2014 to 2015, the overall rate of health insurance coverage increased in people of Hispanic origin by 3.6 percentage points, in Asian people by 1.9 percentage points, and in non-Hispanic white people by 0.9 percentage points.

During that period, the trend in lack of coverage varied by racial and ethnic group. From 1999 to June 2015, among people 18–64 years old, people of Hispanic origin had the highest percentage without coverage (27.2 percent in the first 6 months of 2015), and non-Hispanic white adults had the lowest except in the first 6 months of 2015, when non-Hispanic Asian adults had the lowest percentage. The difference between the highest and lowest percentages of people

---

[1]Defined as people who report as being Asian, Hispanic, black, or American Indian or Alaska Native.

18–64 years old who did not have health insurance among the four racial and ethnic groups narrowed from 1999 to June 2015. The difference was 24.9 percentage points in 1999 (adults of Hispanic origin compared with non-Hispanic white adults) and 19.9 percentage points in the first 6 months of 2015 (adults of Hispanic origin compared with non-Hispanic Asian adults) (NCHS, 2016).

Chen et al. (2016) examined racial and ethnic disparities in health-care access and utilization after the ACA health insurance mandate was fully implemented in 2014. They used the 2011–2014 National Health Interview Survey (NHIS) to examine changes in health-care access and utilization. They noted that the full implementation of the ACA (year indicator, 2014) was associated with substantial reductions in the probabilities of being uninsured, delaying necessary care, and forgoing necessary care, with an increase in the probability of having physician visits compared with the reference year (2011).

A systematic review of 37 studies examined the extent and measurement of racism in health-care providers (Paradies et al., 2014). A number of databases and electronic journal collections were searched for articles published in 1995–2012 (including Medline, CINAHL, PsycInfo, and Sociological Abstracts). The search included published reports (in English) of empirical studies of any design that measured or discussed racism in health-care providers. The studies used a number of measurement approaches and dealt primarily with physicians in the United States. Of the 37 studies, 26 found statistically significant evidence of racist beliefs, emotions, or practices among health-care providers. A 2015 "Perspective" in the *New England Journal of Medicine* (Ansell and McDonald, 2015) noted evidence that physicians hold stereotypes that are based on patients' race that can influence clinical decisions. The authors stated that despite physicians' and medical centers' best intentions to be equitable, black–white disparities persist in patient outcomes, medical education, and faculty recruitment.

A 2002 Institute of Medicine report, *Unequal Treatment*, reviewed hundreds of studies of age, sex, and racial differences in medical diagnoses, treatments, and health outcomes. It concluded that black people received less effective care than white people for each disease studied even after matching for socioeconomic factors and insurance status. It found evidence of the role of bias, stereotyping, and prejudice in perpetuating racial and health disparities. Multiple factors contribute to racial disparities in health-care access and utilization, but unconscious bias on the part of medical professionals might contribute to deficits in the quality of care.

The more recent annual *National Healthcare Quality and Disparities Report* (*QDR*)[2] provides an overview of the quality of health care received by the US population and highlights continued disparities in care that are experienced by different racial and socioeconomic groups (AHRQ, 2017). The 2016 *QDR* states that disparities were getting smaller from 2000 through 2014–2015 but that disparities persist, especially for poor and uninsured populations. Furthermore, although 20 percent of measures show disparities decreasing for black people and people of Hispanic origin, most disparities have not changed more than a small amount for any racial and ethnic groups. More than half the measures[3] show that poor and low-income households had worse care than high-income households; more than 40 percent of the measures

---

[2]The Agency for Healthcare Research and Quality produces the QDR, which is mandated by the US Congress.
[3]The report assesses the performance of our health-care system and identifies strengths, weaknesses, and disparities in access to quality of health care. Quality is described in terms of the National Quality Strategy priorities, which include patient safety, person-centered care, care coordination, effective treatment, healthy living, and care affordability. The report is based on more than 250 measures of quality and disparities covering a broad array of health-care services and settings.

show that middle-income households had worse care than high-income households. Nearly two-thirds of the measures show that uninsured people had worse care than privately insured people.

Sex

Women overall have higher health-care utilization than men. Although it had been thought that women receive health care primarily during child-bearing years for reproductive health, many health-care utilizations occur during and after menopause for such issues as cardiovascular disease and osteoporosis (Owens, 2008). Other studies have shown that women make more primary care visits and receive more diagnostic services, screening services, diet and nutrition counseling, and sexual health care than men even though men generally have higher rates of obesity and cardiovascular problems (Salganicoff et al., 2014).

Among people 18–64 years old, women have higher rates of disability and self-reported fair or poor health status. Among all people 18 years and older, women are more likely to delay or not receive care, or to not receive prescription drugs, because of cost. Women are more likely to have a health-care visit in a given year, to have 10 or more visits, and to have a hospitalization or ED visit (NCHS, 2017b). Those findings indicate that although women utilize health-care resources at greater rates, health-care needs go unmet.

Working Age Adults

The average retirement age in the United States in 2013 was 64 years for men and 62 years for women (Munnell, 2015). However, because of disability or for other reasons, many workers leave the workforce before Social Security retirement age or before they become eligible for pensions or vested savings.

There is no question that increased functional limitations and consequent health-care utilization occurs in people as they age; that is true for working-age people and for older adults (NCHS, 2017b). There has also been an increase in rates of health-care utilization and functional limitation in people 45–64 years old (Freid et al., 2012). About 4 percent of people who were 18–44 years old had self-reported heart disease compared with about 12 percent of people 45–64 years old; corresponding rates of cancer were 2 percent and 7 percent, respectively. Almost one-fourth of people 18–44 years old reported low back pain compared with 35 percent of people 45–64 years old (NCHS, 2017b). Rates of self-reported disability among working-age adults and mental illness among all people 18 years and older have remained stable in recent years (Ahrnsbrak et al., 2017; NCHS, 2017b).

Spoken Language

Many Americans in racial and ethnic minorities experience language barriers and have low or no proficiency in speaking, reading, or comprehending English. In a health-care setting, those barriers can present serious challenges to both patients and providers. A systematic review of studies of language barriers in health care for Latino populations showed that access to care, quality of care, and health status all suffer as a result of language barriers. If a patient does not speak the language of his or her health-care provider, multiple adverse effects on the patient's health care might occur. For example, a patient's inability to understand a provider's diagnosis or treatment plan can lead to poor patient satisfaction, poor compliance, and underuse of services (Timmins, 2002).

Flores (2006) examined language barriers to health care in the United States and noted that some 49.6 million Americans speak a language other than English at home, and 22.3 million have low English proficiency, speaking English less than "very well" according to self-ratings. From 1990 to 2000, the number of Americans who spoke a language other than English at home grew by 15.1 million, and the number with low English proficiency grew by 7.3 million. Many patients who need medical interpreters have no access to them. According to one study, in 46 percent of ED cases that involved patients who had low English proficiency, no interpreter was used (Baker et al., 1996). Few clinicians receive training in working with interpreters; only 23 percent of US teaching hospitals provide any such training, and most of them make it optional (Flores, 2006).

Patients who face language barriers are less likely than their English-speaking counterparts to have a usual source of medical care, receive fewer preventive services, and have a greater likelihood of nonadherence to medication prescriptions. Psychiatric patients who encounter language barriers are more likely than others to receive a diagnosis of a severe psychopathologic condition—but are also more likely to leave the hospital against medical advice. Such patients are less likely than others to return for followup appointments after visits to an ED, and they have higher rates of hospitalization and drug complications (Flores, 2006).

Income and Poverty

Income correlates highly with risk factors for chronic disease: for example, people who have lower family income have higher rates of heart disease, stroke, diabetes, or hypertension, and have four or more common chronic conditions (NCHS, 2017b). People in families whose income is less than 200 percent of the federal poverty level are more likely to be obese and to smoke cigarettes than wealthier people. Adults who live in poverty are also more likely to have self-reported serious psychologic distress, as measured by a series of questions about their perceived mental health.

Economic resources (such as income and wealth) enable access to material goods and services, including health-care services. In 2009–2010, people of all racial and ethnic groups who were 18–64 years old and had a family income below 200 percent of the poverty level were more likely than those who had higher family income to delay seeking or not to receive needed medical care because of cost (NCHS, 2012). From 2000 to 2010, the percentage of people 18–64 years old who did not get or delayed seeking needed medical care during the preceding 12 months because of cost increased in all family income groups. During that period, the percentage who had unmet needs for medical care decreased as family income increased from below 200 percent of the poverty level to 400 percent or more of the poverty level. Failure to receive needed medical care because of cost was equally likely in families below the poverty level and those whose income was 100–199 percent of the poverty level.

More recent findings indicate that in 2014 28.6 percent of adults who were living under the poverty level had one or more ED visits compared with 13.5 percent of adults who were at 400 percent of the poverty level, and 8.1 percent of adults under the poverty level had at least one hospitalization compared with 3.8 percent of adults at 400 percent of the poverty level. Despite the high utilization of health-care services by low-income people, adults under the poverty level reported greater rates of not receiving or of delaying medical care, obtaining prescription drugs, and receiving dental care because of costs than adults who were at 400 percent of the poverty level. Thus, health-care needs of those under the poverty level are still being unmet despite their higher utilization of emergency and hospital services (NCHS, 2017b).

Geography

The extent of urbanization has been shown to be associated with health-care utilization in several ways, including the correlation of residents' sociodemographic characteristics with need, risk factors, and access to care. Communities that differ in urbanization differ in their demographic, environmental, economic, and social characteristics, and those characteristics correlate with the magnitude and types of health problems that the communities face. For example, more-urban counties tend to have more health-care providers per capita, and residents of more-rural counties often live farther from health-care resources.

Most studies have compared aggregated magnitude of urbanization—primarily metropolitan compared with nonmetropolitan areas. However, a few studies have compared utilization by more granular urbanization groupings: metropolitan geographic areas, inner cities of large metropolitan areas, fringes of large cities (sometimes called suburbs), and small metropolitan areas; and two categories of nonmetropolitan areas, namely, large rural areas that contain small population centers and rural areas that contain very small population centers (Ingram and Franco, 2014). Those studies show some differences by magnitude of urbanization, but other differences are more pronounced between suburban fringe areas of cities (which tend to have higher average income) and other areas.

Sociodemographic and Characteristics

Residents of rural areas differ from residents of urban areas in a number of important characteristics that correlate with health-care utilization. Rural residents have low incomes: 17 percent of rural workers earn less than the poverty level ($11,490 per year for an individual) compared with 14.6 percent of urban workers (Mueller et al., 2014). They are more likely to classify themselves as white. The greatest racial and ethnic diversity was found in central counties of large metropolitan areas. In 2010, the population of central counties nationwide was 27 percent Hispanic origin, 17 percent non-Hispanic black, 9 percent non-Hispanic Asian or Pacific Islander, 2 percent people identifying with multiple races, and less than 1 percent non-Hispanic or American Indian or Alaska Native (AI/AN) origin. All those groups except AI/ANs were less likely to live in nonmetropolitan counties than in central counties. Among all regions, fringe counties of large metropolitan areas (suburban areas) had the lowest concentration of people in poverty in 2011 (9–13 percent). The proportions of the populations in poverty in all other urbanization levels were comparable.

Risk Factors

Rural residents have a higher percentage of several risk factors associated with poorer health than urban residents. For example, self-reported obesity rates vary by urbanization and increase with increasing rurality. In 2010–2011, people living in central counties of large metropolitan areas nationwide had the lowest age-adjusted prevalence of obesity, and women in the most rural counties had the highest (Meit et al., 2014). In people 20 years old and over, urbanization patterns in ischemic heart disease (IHD) death rates differed by region. In the South, 2008–2010 IHD death rates were lowest in fringe counties of large metropolitan areas and more than 25 percent higher in the most rural counties. In the Midwest, IHD death rates were highest in the most rural counties.

For the United States as a whole, limitation of activity due to chronic health conditions in adults is more common in nonmetropolitan counties than in large metropolitan counties. In all

regions except the Midwest, the rate of activity limitation due to chronic health conditions in both men and women generally increases as rurality increases.

Utilization

Using the more aggregated metropolitan/nonmetropolitan grouping, data show that adults who live in nonmetropolitan areas are more likely to report having 10 or more visits to doctors' offices, visits to EDs, or home visits in the preceding year than are people who live in metropolitan areas (NCHS, 2017b). In particular, they have higher rates of ED visits. Nonmetropolitan residents have a slightly higher rate of at least one hospital stay during the year and a similar rate of two or more hospital stays (NCHS, 2017b). Inpatient hospital discharge rates of people 18–64 years old were higher in small metropolitan counties than in metropolitan and nonmetropolitan counties. The average length of stay was highest in central counties of large metropolitan areas (Meit et al., 2014).

Access

Douthit et al. (2015) conducted a literature review of the provision of health care and access in rural areas of the United States. Their findings indicate a reluctance to seek health care because of cultural and financial constraints, which are often compounded by a scarcity of services, a lack of trained physicians, insufficient public transportation, and poor availability of broadband Internet services. Rural residents were found to have poorer health than urban residents, and rural areas had more difficulty in attracting and retaining physicians than their urban counterparts.

The urbanization pattern of the supply of physicians and other providers depends on specialty. However, physician supply generally decreases steadily as rurality increases both nationally and regionally. The National Center for Health Statistics (2017b) NHIS[4] found that in 2015, about 10 percent of people who were 18–64 years old had difficulty in accessing needed medical care, which included experiencing delays or not receiving needed care because of cost. The difficulty varied by region: people in the South and the Midwest had the most difficulty, and those in the Northeast and West had the least (NCHS, 2017b).

Urban and rural locations differ in transit options, which affects whether patients can access care. Syed et al. (2013) studied issues of cost, availability of transit, distance to health-care providers, and travel burden by time and distance. Their literature review found that transportation barriers affect health-care access in as little as 3 percent or as much as 67 percent of the population, depending on the area. Their findings collectively suggest that lack or inaccessibility of transportation might be associated with less health-care utilization, lack of regular medical care, and missed appointments.

Residents of central counties of large metropolitan areas and nonmetropolitan counties have similarly high percentages of residents who lack health insurance. In general, central counties of large metropolitan areas often have the most adverse health measures in the Northeast and Midwest, and nonmetropolitan counties tend to fare the worst in the South and West (Meit et al., 2014). Including all income levels, fringe counties of large metropolitan areas had the largest proportion of privately insured people less than 65 years old in each of the four

---

[4]The National Center for Health Statistics NHIS notes that respondents are civilian noninstitutionalized persons; thus active-duty members of the armed forces, incarcerated persons, and people in long-term care institutions are excluded.

regions. The coverage gaps in rural America exist in large part because rural Americans have less access to private insurance. Only 64 percent of rural employers offer their workers health insurance compared with 71 percent in urban areas (Coburn et al., 2009). The prevalence of such jobs as farming and contracting means that self-employment is more prevalent in rural America. Not only are the self-employed in all parts of the country insured at lower rates than wage earners, but the self-employed in rural America are insured at even lower rates than the self-employed in urban areas.

Geographic markets also differ with respect to managed care penetration, payer involvement, and state and local oversight (Horwitz and Nichols, 2011; Colla et al., 2016). Physicians in rural areas receive 20 percent of their revenue from Medicaid compared with 17 percent for physicians in urban areas (Bailey, 2012). Up to 84 percent of rural physicians accept new Medicaid patients compared with 65 percent of urban physicians (UnitedHealth Center for Reform & Modernization, 2011).

Geographic Practice Patterns

Variation in surgical rates by geographic area, particularly hospital referral regions, is high and represents both gaps in outcomes research and poor patient decision quality. Outcomes differ from place to place even when patient differences are controlled for. The Dartmouth Atlas Project has conducted extensive research designed to examine local differences in practice patterns (Goodney et al., 2015). It used the hospital referral regions as the geographic unit of study. In 2007 and 2011, rates of bariatric surgery in Medicare beneficiaries varied by a factor of more than 20 and rates of therapeutic endovascular interventions by a factor of more than 6. The rate of open leg bypass surgery was 4.1 per 1,000 Medicare beneficiaries who had diabetes and peripheral artery disease; this rate varied from under 2 to more than 9 procedures per 1,000 people among hospital referral regions.

In 2013, the Institute of Medicine report *Variation in Health Care Spending: Target Decision Making, Not Geography* evaluated geographic variation in magnitude and growth of health-care spending by people in the United States who have Medicare, Medicaid, private insurance, or no insurance. The report presented findings of analyses of traditional, fee-for-service Medicare (and to a smaller extent Medicare Advantage, or Part C) and commercial insurance. It noted that because of methodologic challenges and data limitations, it did not include separate analyses of variation in the Medicaid and uninsured populations, although estimates of spending by those two groups are included in the area-wide estimates of total health-care spending. The report's findings are instructive in examining geographic determinants of health-care use:

- Geographic variation in spending and utilization persists among geographic units and health-care services and over time.
- After adjustment for differences in the age, sex, and health status of beneficiaries, geographic variation in spending on both Medicare and commercial insurance is not further explained by other beneficiary demographic factors, insurance plan factors, or market-level characteristics. In fact, after controlling for all factors measurable within the data used for the analysis, much of the variation remains unexplained.
- Variation in spending and utilization remains as units of analysis get progressively smaller (hospital referral regions, hospital service area, hospital, practice, and individual provider). Hospital referral region-level quality is not consistently related to spending or utilization by either Medicare beneficiaries or the commercially insured.

PEOPLE WITH DISABILITIES

Disability is a multidimensional concept. Some health conditions associated with disability result in poor health and extensive health-care needs, but others do not. The disabled population is clinically diverse. Some members have multiple chronic conditions that are stable with treatment and will persist for years; others have extreme functional limitations. Some have mostly severe, persistent behavioral health challenges; others have conditions that are greatly exacerbated by social factors such as lack of housing, food, and supportive personal relationships (Krahn et al., 2015; Meade et al., 2015; Blumenthal et al., 2016). The committee's use of the word *disability* will vary with the literature that it reviewed.

The term *disability* implies that there are limitations in a person's ability to function in one or more ways. But types of impairment also differ substantially and might more or less limit a person's ability to function. They might:

- Impair a person's body structure or function, or mental functioning; examples of impairment are loss of a limb, loss of vision, and memory loss.
- Limit activity, such as difficulty seeing, hearing, walking, or problem-solving.
- Restrict participation in normal daily activities, such as working, engaging in social and recreational activities, and obtaining health-care and preventive services (ODPHP, 2017b).

Disability can be caused by or be related to genetic disorders, injuries, illness, or environmental exposures. Disabilities can be temporary, progressive, or intermittent. Thus, it is difficult to generalize about the relationship between disability and health-care utilization without targeting specific causes, diseases, or conditions. However, people who have disabilities have the same general health-care needs as everyone else, and therefore need access to health-care services (WHO, 2017).

Some diseases or conditions associated with disability are common; others are rare. For example, in 2015 one-fourth of people who were 18–64 years old reported difficulty in performing a basic activity, and 12.5 percent reported complex-activity limitation (NCHS, 2017b).

Without adjustment, population rates of seven selected disabilities among all adults (not limited to working-age adults) increased substantially from 1998 to 2011. The absolute percentage change was greatest for movement difficulties, from 19.3 percent in 1998 to 23.3 percent in 2011. After separate adjustments for trends in age, race and ethnicity, and body mass index distributions, six disability types continued to show increased rates over time; the exception was sensory disabilities. Poor education, poverty, and unemployment remained associated with disability (Iezzoni et al., 2014). People who report disability are at higher risk for poor health outcomes such as obesity, hypertension, falls-related injuries, and mood disorders, including depression (An et al., 2015; Krahn et al., 2015; Meade et al., 2015; CDC, 2017).

People with disabilities use more health-care services than people who do not, in part because they have greater need for medical and health services to treat their conditions (NCHS, 2017b). One-third of adults who had disabilities had at least one ED visit in 2015, compared to 13 percent of adults who had no disability. Some 29 percent of people who had disabilities had 10 or more visits to doctors or EDs or had home health-related visits compared with 8 percent of adults who had no disability (NCHS, 2017b).

People who have disabilities also face a number of barriers to access to health care that are specific to their individual limitations in function (Lagu et al., 2014; Meade et al., 2015). The barriers include physical access and absence of working elevators or ramps, automatic doors, hallways and doors wide enough to accommodate wheelchairs, and accessible parking; policies that discriminate against people with disabilities and the absence of policies in place and enforced that are designed to accommodate people with disabilities; and lack of accommodation for barriers to communication, including large print materials, sign language interpreters, and staff who are willing to try to communicate with impaired patients during scheduling or other interactions.

SUMMARY AND CONCLUSIONS

The health-care delivery system has undergone much change in the past few decades: new and improved drugs, devices, procedures, tests, and imaging machinery have changed patterns of care and sites where care is provided. The growth in ambulatory surgery has been influenced by improvements in anesthesia and analgesia and by the development of noninvasive or minimally invasive techniques. New and improved, and less invasive, procedures are available to treat people for a number of previously untreatable conditions in a variety of new sites of care, and even in physicians' offices. New drugs can cure disease or prolong survival of disease, although often at increased cost or with increased utilization. However, the availability of newer and improved types of health-care services does not mean that they are equally available to all Americans.

People use health-care services to diagnose, cure, or ameliorate disease or injury; to improve or maintain function; or even to obtain information about their health status and prognosis. Many factors affect health-care utilization, including need. The need for services affects differential use of health utilization for specific populations. Ideally, need is the major determinant of health-care utilization, but other factors clearly have an impact. They include poverty and its correlates, geographic area of residence, race and ethnicity, sex, age, language spoken, and disability status. The ability to access care—including whether it is available, timely and convenient, and affordable—affects health care utilization.

For people who have disabilities, accessing health care can be demanding. Many factors facilitate and hinder access to needed health care. Disability correlates with increased health-care utilization, and people who have disabilities often have worse overall health status, are poorer, and have a higher prevalence of poor health behaviors such as smoking and obesity. They also have poorer overall access because of provider discrimination, provider failure to make accommodations, and inadequate communication with providers.

REFERENCES

Agarwal, R., O. Mazurenko, and N. Menachemi. 2017. High-deductible health plans reduce health care cost and utilization, including use of needed preventive services. *Health Affairs (Millwood)* 36(10):1762–1768.

Ahrnsbrak, R., J. Bose, S. L. Hedden, R. N. Lipari, and E. Park-Lee. 2017. *Key substance use and mental health indicators in the United States: Results from the 2016 National Survey on Drug Use and Health.* Rockville, MD: Center for Behavioral Health Statistics and Quality, Substance Abuse and Mental Health Services Administration. https://www.samhsa.gov/data/sites/default/files/NSDUH-FFR1-2016/NSDUH-FFR1-2016.htm (accessed December 26, 2017).

AHRQ (Agency for Healthcare Research and Quality). 2010. *2009 National Healthcare Quality and Disparities Reports.* Rockville, MD: AHRQ. https://archive.ahrq.gov/research/findings/nhqrdr/nhqrdr09/qrdr09.html (accessed June 13, 2017).

AHRQ. 2017. *2016 National Healthcare Quality and Disparities Reports.* Rockville, MD: AHRQ. https://www.ahrq.gov/sites/default/files/wysiwyg/research/findings/nhqrdr/nhqdr16/2016qdr.pdf (accessed June 13, 2017).

An, R., F. Andrade, and C. Y. Chiu. 2015. Overweight and obesity among U.S. adults with and without disability, 1999–2012. *Preventive Medicine Reports* 2:419–422.

Andersen, R., and J. F. Newman. 2005. Societal and individual determinants of medical care utilization in the United States. *The Milbank Quarterly* 83(4):10.1111/j.1468-0009.2005.00428.x.

Ansell, D. A., and E. K. McDonald. 2015. Bias, black lives, and academic medicine. *New England Journal of Medicine* 372(12):1087–1089.

Bailey, J. 2012. *Medicaid and rural America.* Lyons, NE: Center for Rural Affairs. http://files.cfra.org/pdf/Medicaid.pdf (accessed November 7, 2017).

Baker, D. W., R. M. Parker, M. V. Williams, W. C. Coates, and K. Pitkin. 1996. Use and effectiveness of interpreters in an emergency department. *JAMA* 275(10):783–788.

Blumenthal, D., B. Chernof, T. Fulmer, J. Lumpkin, and J. Selberg. 2016. Caring for high-need, high-cost patients—an urgent priority. *New England Journal of Medicine* 375(10):909–911.

Braveman, P., and L. Gottlieb. 2014. The social determinants of health: It's time to consider the causes of the causes. *Public Health Reports* 129(Suppl 2):19–31.

CDC (Centers for Disease Control and Prevention). 2017. *Overweight and obesity among people with disabilities.* Atlanta, GA: CDC. https://www.cdc.gov/ncbddd/disabilityandhealth/documents/obesityfactsheet2010.pdf (accessed October 31, 2017).

Chen, J., A. Vargas-Bustamante, K. Mortensen, and A. N. Ortega. 2016. Racial and ethnic disparities in health care access and utilization under the Affordable Care Act. *Medical Care* 54(2):140–146.

Coburn, A. F., A. C. MacKinney, T. D. McBride, K. J. Mueller, R. T. Slifkin, and E. Ziller. 2009. *Assuring health coverage for rural people through health reform.* Princeton, NJ: Rural Policy Research Institute. http://www.rupri.org/Forms/Health_ReformBrief_Oct09.pdf (accessed November 7, 2017).

Colla, C. H., V. A. Lewis, E. Tierney, and D. B. Muhlestein. 2016. Hospitals participating in ACOs tend to be large and urban, allowing access to capital and data. *Health Affairs (Millwood)* 35(3):431–439.

Davis, K., and J. Ballreich. 2014. Equitable access to care—how the United States ranks internationally. *New England Journal of Medicine* 371(17):1567–1570.

Douthit, N., S. Kiv, T. Dwolatzky, and S. Biswas. 2015. Exposing some important barriers to health care access in the rural USA. *Public Health* 129(6):611–620.

Fang, J., G. Zhao, G. Wang, C. Ayala, and F. Loustalot. 2016. Insurance status among adults with hypertension—the impact of underinsurance. *Journal of the American Heart Association: Cardiovascular and Cerebrovascular Disease* 5(12):e004313.

Figueroa, J. F., A. B. Frakt, Z. M. Lyon, X. Zhou, and A. K. Jha. 2017. Characteristics and spending patterns of high cost, non-elderly adults in Massachusetts. *Healthcare (Amsterdam, Netherlands)* 5(4):165–170.

Flores, G. 2006. Language barriers to health care in the United States. *New England Journal of Medicine* 355(3):229–231.

Freid, V. M., A. B. Bernstein, and M. A. Bush. 2012. Multiple chronic conditions among adults aged 45 and over: Trends over the past 10 years. *NCHS Data Brief* (100):1–8.

Goodney, P., N. Dzebisashvili, D. Goodman, and K. Bronner. 2015. *Variation in the care of surgical procedures: A Dartmouth Atlas of Care Series.* Dartmouth, NH: The Dartmouth Atlas of Health Care. http://www.dartmouthatlas.org/downloads/atlases/Surgical_Atlas_2014.pdf (accessed December 27, 2017).

Horwitz, J. R., and A. Nichols. 2011. Rural hospital ownership: Medical service provision, market mix, and spillover effects. *Health Services Research Journal* 46(5):1452–1472.

Iezzoni, L. I., S. G. Kurtz, and S. R. Rao. 2014. Trends in U.S. adult chronic disability rates over time. *Disability and Health Journal* 7(4):402–412.

Ingram, D. D., and S. J. Franco. 2014. 2013 NCHS urban-rural classification scheme for counties. *Vital Health Statistics Series* 2(166):1–73.

IOM (Institute of Medicine). 1993. *Access to Health Care in America.* Washington, DC: National Academy Press.

IOM (Institute of Medicine). 2002. *Unequal treatment: Confronting racial and ethnic disparities in health care.* Washington, DC: The National Academies Press.

Kale, M. S., T. F. Bishop, A. D. Federman, and S. Keyhani. 2013. Trends in the overuse of ambulatory health care services in the United States. *JAMA Internal Medicine* 173(2):142–148.

KFF (Kaiser Family Foundation). 2016. *Key facts about the uninsured population.* Menlo Park, CA: The Henry J. Kaiser Family Foundation. https://www.kff.org/uninsured/fact-sheet/key-facts-about-the-uninsured-population (accessed February 5, 2018).

Kielb, E. S., C. N. Rhyan, and J. A. Lee. 2017. Comparing health care financial burden with an alternative measure of unaffordability. *Inquiry* 54:46958017732960.

Krahn, G. L., D. K. Walker, and R. Correa-De-Araujo. 2015. Persons with disabilities as an unrecognized health disparity population. *American Journal of Public Health* 105(Suppl 2):S198–S206.

Kressin, N. R., and P. W. Groeneveld. 2015. Race/ethnicity and overuse of care: A systematic review. *The Milbank Quarterly* 93(1):112–138.

Lagu, T., L. I. Iezzoni, and P. K. Lindenauer. 2014. The axes of access—improving care for patients with disabilities. *New England Journal of Medicine* 370(19):1847–1851.

Lavarreda, S. A., E. R. Brown, and C. D. Bolduc. 2011. Underinsurance in the United States: An interaction of costs to consumers, benefit design, and access to care. *Annual Review of Public Health* 32:471–482.

Levesque, J.-F., M. F. Harris, and G. Russell. 2013. Patient-centered access to health care: Conceptualising access at the interface of health systems and populations. *International Journal for Equity in Health* 12(1):18.

Lyu, H., T. Xu, D. Brotman, B. Mayer-Blackwell, M. Cooper, M. Daniel, E. C. Wick, V. Saini, S. Brownlee, and M. A. Makary. 2017. Overtreatment in the United States. *PLoS ONE* 12(9):e0181970.

MACPAC (Medicaid and CHIP Payment and Access Commission). 2016. *Medicaid access in brief: Adults' experiences in obtaining medical care.* Washington, DC: MACPAC. https://www.macpac.gov/wp-content/uploads/2016/11/Adults-Experiences-in-Obtaining-Medical-Care.pdf (accessed December 27, 2017).

Magge, H., H. J. Cabral, L. E. Kazis, and B. D. Sommers. 2013. Prevalence and predictors of underinsurance among low-income adults. *Journal of General Internal Medicine* 28(9):1136–1142.

Meade, M. A., E. Mahmoudi, and S. Y. Lee. 2015. The intersection of disability and healthcare disparities: A conceptual framework. *Disability and Rehabilitation* 37(7):632–641.

Meit, M., A. Knudson, T. Gilbert, A. T.-C. Yu, E. Tanenbaum, E. Ormson, S. TenBroeck, A. Bayne, and S. Popat. 2014. *The 2014 update of the rural-urban chartbook.* Bethesda, MD: Rural Health Reform Policy Research Center. https://ruralhealth.und.edu/projects/health-reform-policy-research-center/pdf/2014-rural-urban-chartbook-update.pdf (accessed December 27, 2017).

Mueller, K. J., J. P. Lundblad, A. Mackinney, T. McBride, and S. D. Watson. 2014. *The current and future role and impact of Medicaid in rural health.* http://www.rupri.org/Forms/HealthPanel_Medicaid_Sept2012.pdf (accessed February 5, 2018).

Munnell, A. H. 2015. *The average retirement age—an update*. Boston, MA: Center for Retirement Research at Boston College. http://crr.bc.edu/wp-content/uploads/2015/03/IB_15-4.pdf (accessed November 7, 2017).

NCHS (National Center for Health Statistics). 2003. *Health care in America: Trends in utilization*. Hyattsville, MD: US Department of Health and Human Services. https://www.cdc.gov/nchs/data/misc/healthcare.pdf (accessed March 1, 2017).

NCHS. 2012. Health, United States. In *Health, United States, 2011: With special feature on socioeconomic status and health*. Hyattsville, MD: National Center for Health Statistics (US).

NCHS. 2016. Health, United States. In *Health, United States, 2015: With special feature on racial and ethnic health disparities*. Hyattsville, MD: National Center for Health Statistics (US).

NCHS. 2017a. *NCHS fact sheet: Health insurance and access to care*. https://www.cdc.gov/nchs/data/factsheets/factsheet_hiac.pdf (accessed November 7, 2017).

NCHS. 2017b. Health, United States. In *Health, United States, 2016: With chartbook on long-term trends in health*. Hyattsville (MD): National Center for Health Statistics (US).

ODPHP (US Department of Health and Human Services, Office of Disease Prevention and Health Promotion). 2017a. *Foundation health measures: Determinants of health*. Washington, DC: US Department of Health and Human Services. https://www.healthypeople.gov/2020/about/foundation-health-measures/Determinants-of-Health (accessed December 27, 2017).

ODPHP. 2017b. *Healthy People 2020 topics and objectives: Disability and health*. Washington, DC: US Department of Health and Human Services. https://www.healthypeople.gov/2020/topics-objectives/topic/disability-and-health (accessed December 27, 2017).

OMH (US Department of Health and Human Services, Office of Minority Health). 2011. *HHS action plan to reduce racial and ethnic health disparities*. Washington, DC: US Department of Health and Human Services. https://minorityhealth.hhs.gov/npa/files/plans/hhs/hhs_plan_complete.pdf (accessed November 6, 2017).

Owens, G. M. 2008. Gender differences in health care expenditures, resource utilization, and quality of care. *Journal of Managed Care & Specialty Pharmacy* 14(3 Suppl):2–6.

Paradies, Y., M. Truong, and N. Priest. 2014. A systematic review of the extent and measurement of healthcare provider racism. *Journal of General Internal Medicine* 29(2):364–387.

Salasky, V., R. L. Yang, J. Datta, H. L. Graves, J. A. Cintolo, C. Meise, G. C. Karakousis, B. J. Czerniecki, and R. R. Kelz. 2014. Racial disparities in the use of outpatient mastectomy. *Journal of Surgical Research* 186(1):16–22.

Salganicoff, A., U. Ranji, A. Beamesderfer, and N. Kurani. 2014. *Women and health care in the early years of the Affordable Care Act: Key findings from the 2013 Kaiser women's health survey*. Menlo Park, CA: Kaiser Family Foundation. https://www.kff.org/womens-health-policy/report/women-and-health-care-in-the-early-years-of-the-aca-key-findings-from-the-2013-kaiser-womens-health-survey (accessed February 5, 2018).

Schoen, C., R. Osborn, D. Squires, and M. M. Doty. 2013. Access, affordability, and insurance complexity are often worse in the United States compared to ten other countries. *Health Affairs (Millwood)* 32(12):2205–2215.

Squires, D., and C. Anderson. 2015. US health care from a global perspective: Spending, use of services, prices, and health in 13 countries. *Issue Brief (Commonwealth Fund)* 15:1–15.

Syed, S. T., B. S. Gerber, and L. K. Sharp. 2013. Traveling towards disease: Transportation barriers to health care access. *Journal of Community Health* 38(5):976–993.

Thomas-Henkel, C., and M. Schulman. 2017. *Screening for social determinants of health in populations with complex needs: Implementation considerations*. Washington, DC: Center for Health Care Strategies, Inc. https://www.chcs.org/media/SDOH-Complex-Care-Screening-Brief-102617.pdf (accessed December 27, 2017).

Timmins, C. L. 2002. The impact of language barriers on the health care of Latinos in the United States: A review of the literature and guidelines for practice. *Journal of Midwifery & Women's Health* 47(2):80–96.

UnitedHealth Center for Reform & Modernization. 2011. *Modernizing rural health care: Coverage, quality and innovation*. Washington, DC: UnitedHealth. http://www.unitedhealthgroup.com/~/media/UHG/PDF/2011/UNH-Working-Paper-6.ashx (accessed November 7, 2017).

USCB (US Census Bureau). 2016. Health insurance coverage in the United States: 2015. In *Current Population Reports*. Washington, DC: US Government Printing Office. https://www.census.gov/content/dam/Census/library/publications/2016/demo/p60-257.pdf (accessed November 7, 2017).

WHO (World Health Organization). 2017. Health impact assessment (HIA), determinants of health. Geneva, Switzerland: WHO. http://www.who.int/hia/evidence/doh/en (accessed March 8, 2017).

Williams, D. R., and R. Wyatt. 2015. Racial bias in health care and health: Challenges and opportunities. *JAMA* 314(6):555–556.

3

Changing Patterns of Health Insurance and Health-Care Delivery

This chapter describes recent changes in the structure of health insurance and health-care delivery in the United States and how the changes have altered how people who have chronic diseases and disabling conditions receive health care. Over the past several decades, there have been many efforts to change incentive structures in health care, all with the goal of reducing health-care costs while improving patient health outcomes. Most important among them was the Patient Protection and Affordable Care Act (ACA), which was signed into law on March 23, 2010. The ACA was the largest federal health policy initiative since the creation of Medicare and Medicaid. It brought about structural changes in the health-care system, which included efforts to improve access to health-care insurance (through expansion of the Medicaid program and through subsidized and lower-cost health insurance plans made available through new health insurance marketplaces, or exchanges), elimination of pre-existing condition restrictions in coverage, elimination of lifetime caps on health-care spending, and slowing of growth in health-care costs through innovative payment reforms.

Although the details differ, most reforms brought about by the ACA and other efforts in recent decades have sought to reduce costs and improve patient health by expanding access to care, introducing management and coordination of care, improving quality of care, shifting risk from insurers to providers and patients, and shifting care provision from costly settings—such as hospitals, emergency departments (EDs), and long-term care facilities—to less expensive outpatient, office, community, and home settings. High-cost, high-need people have been a focus of most reform efforts because they have the greatest need and thus account for a disproportionate share of health-care spending.

The ways in which people who have chronic diseases and disabling conditions receive health care have changed in fundamental ways in terms of the kind of care they receive, how much care they receive, which providers administer the care, in which settings they receive care, and even the time of day at which they receive care, for example, during the workday or after work.

In the sections that follow, the committee begins with an overview of health insurance in the United States and of the many changes brought about by the ACA. That is followed by a discussion of the health-care delivery system, which explains how delivery system reforms brought about by the ACA and other efforts have altered the structure of health-care delivery. The committee concludes by summarizing the research evidence on how the utilization patterns

and health outcomes of people who have chronic diseases and disabling conditions have evolved in response to those changes.

HEALTH INSURANCE IN THE UNITED STATES

Health care in the United States is financed by a combination of public and private insurance, employers, and individuals who pay out of pocket. In 2015, 37 percent of the US population received health care through a public insurance program at some time (USCB, 2016). The major public insurance systems are Medicare and Medicaid. Medicare is a national health insurance program for people over 65 years old, people who have end-stage renal disease or amyotrophic lateral sclerosis, and people who have long-term disabilities once they have qualified for Social Security Disability Insurance (SSDI). It is paid for through a combination of Medicare payroll tax revenues, federal tax revenues, and beneficiary premium payments (and a small amount of state funding for the Medicare Part D prescription-drug benefit). In 2016, Medicare benefit payments totaled $675 billion and accounted for 15 percent of the federal budget, according to a report by the Kaiser Family Foundation (2017a).

Medicaid is a means-tested public insurance program that is jointly funded by the federal and state governments, but is administered by the states. Before the ACA, Medicaid covered people who were categorically eligible for benefits on the basis of income and other requirements determined at the state level. Eligibility categories include low-income children and their families, low-income people who are 65 and older, and low-income adults and children who have disabilities. Some states voluntarily extended Medicaid to other eligibility categories, such as people who have high medical expenses and the long-term unemployed. Total Medicaid spending was $574.2 billion in the federal fiscal year (FY) 2016 (KFF, 2016a).

According to a report by the Kaiser Family Foundation (2015a), Medicaid is the major insurer, public or private, that provides comprehensive coverage for institutional and community-based long-term services and supports (LTSS), which is arguably the most important form of service for people who have disabilities and need assistance with daily self-care tasks. Since the Supreme Court's *Olmstead* decision in 1999, Medicaid has shifted from providing LTSS to people who have disabilities in institutional settings, such as hospitals and long-term care facilities, toward providing LTSS in home and community settings (KFF, 2015a). Although Supplemental Security Income (SSI) qualification grants categorical eligibility for Medicaid, people who are not enrolled or who might be applying for SSI or SSDI but who need long-term services and supports can obtain Medicaid coverage if their income and assets are below designated thresholds. In some states, people who have somewhat higher incomes can qualify if they meet disability-related functional criteria and, in some cases, pay a monthly "buy-in" premium (KFF, 2015a). The ability to buy into Medicaid is critical for many low-income people who have disabilities and require self-care assistance in the home or community setting in order to work; private insurance plans, including employer-sponsored plans, do not provide complete coverage of LTSS. The ACA, by expanding access to Medicaid coverage, extended that benefit to more people who have disabilities. Medicaid spending for institutional and community-based LTSS totaled more than $123 billion in 2013 and accounted for 28 percent of total Medicaid service expenditures in that year and 51 percent of total national spending on LTSS (KFF, 2015a). In addition, the federal government provides funding to federally qualified health centers whose mission is to provide direct medical services to the uninsured.

Other public insurance systems include more targeted programs, such as the Children's Health Insurance Program (CHIP), a means-tested health insurance program for uninsured children in low-income families (administered through Medicaid in some states but as a separate program in others); the Indian Health Service (IHS)[1]; the US Department of Defense (DOD) health-care system (which provides health care for active-duty and retired US military); the DOD disability system (which provides SSDI benefits for injuries sustained during military service); and the US Department of Veterans Affairs (VA) health system, which provides medical care to veterans, many of whom qualify for disability benefits through VA and through SSDI or SSI.[2]

Private health insurance is the most common form of health insurance in the United States: 67.2 percent of the population had private coverage at some point during 2015 (USCB, 2016). Private health insurance continues to be predominantly employer based. In 2015, 55.7 percent had coverage through an employer, and 16.3 percent purchased private individual coverage directly from an insurer (USCB, 2016).[3] Employers offer health insurance as a tax-advantaged benefit to employees, paying a portion of the premium for employees and their dependents. Although the employer share of health insurance premiums is considered an expense for employers like other forms of compensation, employer contributions are tax-free to employees, and employees can pay for their share of health insurance premiums on a pretax basis through payroll deductions. Before the ACA, dependent children could remain on their parents' insurance policies through the age of 18 years or until completion of a college education, but they could have a gap in insurance coverage if they did not start jobs before the coverage lapsed. After the ACA, dependents could remain on their parents' policies through the age of 26 years.

As health-care costs have risen in recent decades, employers have asked employees to share increasingly in the cost of their health care. Employees now pay a higher share of premium costs and face higher coinsurance, copayments, and deductibles than a decade ago (see Figure 3-1). For instance, while the average premium has increased by 58 percent since 2006, the average employee contribution to the premium has increased by 77 percent (KFF, 2016b).

Moreover, employees are increasingly likely to face greater cost-sharing in the form of high deductibles (see Figure 3-2). About 29 percent of people who have employer-sponsored health insurance are enrolled in a high-deductible health plan (HDHP) (KFF, 2016b). By not providing first-dollar coverage for health-care services, HDHPs create strong incentives for people to reduce consumption of health-care services. People enrolled in HDHPs with deductibles of at least $1,300 for one person ($2,600 for a family plan) can save for medical expenses on a pretax basis in health savings accounts (HSAs). If not spent during a calendar year, HSA savings roll over to the next year with interest. Some employers offer HSAs as an employment benefit. Although HDHPs are intended to reduce low-value care and encourage selection of lower-priced providers, recent evidence shows that they result in reductions not only in low-value care but in potentially high-value care (Brot-Goldberg et al., 2017).

---

[1]IHS, an agency in the US Department of Health and Human Services, is responsible for providing federal health services to American Indians and Alaska Natives.

[2]Adjusted for inflation to 2014 dollars, VA disability compensation of veterans amounted to $54 billion in 2013 (CBO, 2014).

[3]Coverage categories are not mutually exclusive; some people switch coverage during a year or have multiple forms of coverage.
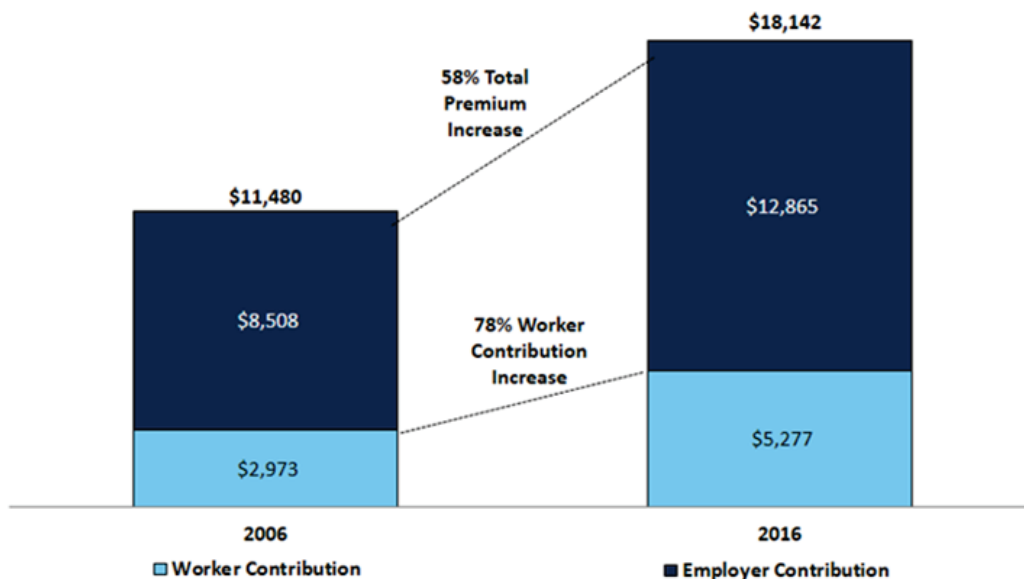
FIGURE 3-1 Average annual health insurance premiums and worker contributions for family coverage, 2006 and 2016.
SOURCE: KFF, 2016b.
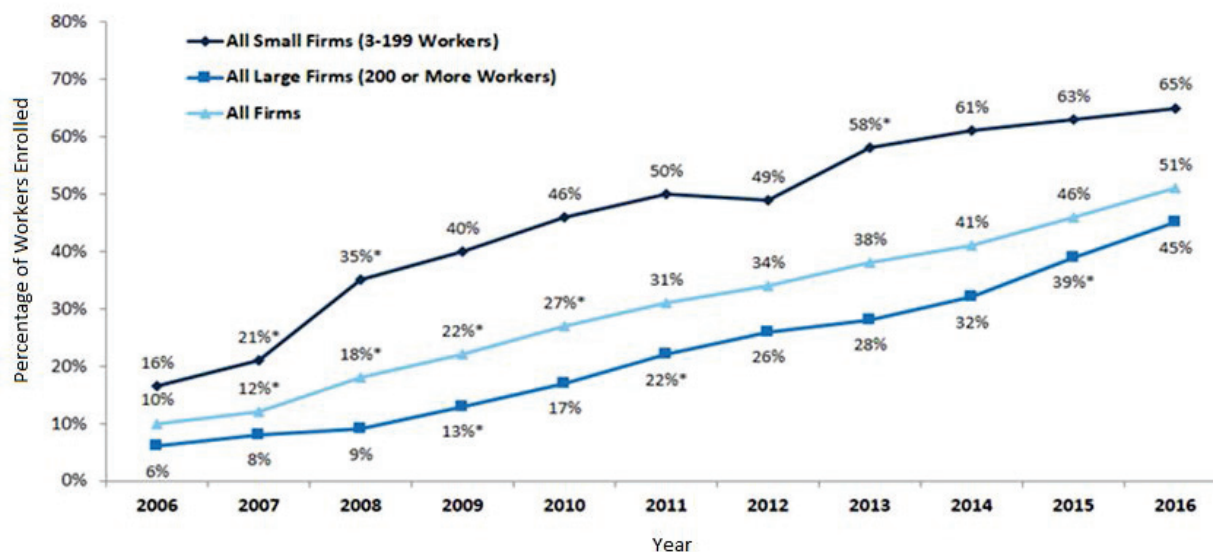
FIGURE 3-2 Percentage of covered workers enrolled in a health insurance plan with a general deductible of $1,000 or more for single coverage, by company size, 2006–2016.
NOTES: *Significantly different from estimate for the previous year shown (p <0.05).
These estimates include workers enrolled in HDHP/SO (high-deductible health plan with savings option) and other plan types. Average general annual health plan deductibles for PPOs (preferred provider organization), POS (point-of-service) plans, and HDHP/SOs are for in-network services.
SOURCE: KFF, 2016b.

Smaller employers purchase health insurance for their employees through the small-group market, which is more expensive than health insurance sold through the large-group market because small employers have fewer employees among whom to spread the health-expenditure risk. The smaller populations in these plans make them more vulnerable to adverse selection—the tendency for those with higher expected health-care expenditures both to sign up for health insurance and to select plans that have more generous coverage. The same is true of the individual market, in which people can purchase private insurance directly from some insurers. Before the ACA, individual insurance plans were considered to pose a high risk to insurers because people who had higher expected utilization were more likely to sign up for health insurance, and this would result in severe adverse selection. When that occurred, insurers raised premiums to cover the higher claims costs, which in turn caused healthier people to leave the plans. That cycle repeated until only high-cost participants remained and the plans terminated.

The risk of adverse selection motivates many structural features of private health insurance that are designed to ensure that health plans have large risk pools with sufficient healthy, low-cost participants. In the individual market, insurance companies would protect themselves financially by using medical underwriting (charging higher premiums for those who have chronic conditions) and by precluding benefits for pre-existing medical conditions for a fixed period. Adverse selection is also why most states have created high-risk pools as a way of guaranteeing that the sickest, highest-cost people, who would otherwise be uninsurable, have access to health insurance coverage. High-risk insurance plans have higher premiums than regular insurance plans, but premiums are regulated and subject to caps (KFF, 2016c).

In 2009, the year before passage of the ACA, about 52 million people, or 15 percent of the US population, lacked health insurance. This included low-income people who did not meet Medicaid income limits or categorical eligibility and working people, usually those who were self-employed or working for a business that did not offer health insurance as a benefit. But lack of insurance did not necessarily mean total lack of medical care, owing to the Emergency Medical Treatment and Labor Act (EMTALA) and access to federally qualified health centers. EMTALA ensures that EDs provide patients with emergency care regardless of their insurance status or ability to pay (CMS, 2012). EMTALA guarantees universal emergency care access for all Americans, but it is an unfunded mandate that is partially addressed through Medicaid disproportionate share hospital (DSH) payments.[4] Hospitals bear the burden of providing not only uncompensated emergency care to patients but nonurgent services inasmuch as many of the uninsured use EDs for all their health-care needs, knowing they will not be turned away (American College of Emergency Physicians, 2016). EMTALA ensures access to care for the uninsured, but ED visits are expensive and tend to result in people flowing back into the hospital for reasons that could have been avoided with adequate primary and specialty care.

A major goal of the ACA was to extend health insurance coverage to 32 million uninsured people in the United States. The ACA had two major components: expansion of the

---

[4]Federal law requires that state Medicaid programs make DSH payments to qualifying hospitals that serve a large number of Medicaid and uninsured people. Federal law establishes an annual DSH allotment for each state that limits federal financial participation (FFP) for total statewide DSH payments made to hospitals. Federal law also limits FFP for DSH payments through the hospital-specific DSH limit. Under the hospital-specific DSH limit, FFP is not available for state DSH payments that are more than a hospital's eligible uncompensated care cost, which is the cost of providing inpatient hospital and outpatient hospital services to Medicaid patients and the uninsured minus payments received by the hospital by or on behalf of the patients in question (see https://www.medicaid.gov/medicaid/financing-and-reimbursement/dsh/index.html, accessed February 5, 2018).

Medicaid program and new structures to support the individual and small-group health insurance markets.

The ACA eliminated the concept of categorical eligibility and replaced it with standard eligibility criteria of 138 percent of the federal poverty level. In 2012, the Supreme Court ruled that the federal government could not force the states to expand Medicaid coverage. As a result, only 32 states and the District of Columbia elected to expand Medicaid (KFF, 2017b).

For the individual and small-group markets, the ACA established health insurance exchanges in states to allow individuals and small groups to buy standard insurance policies with income-based subsidies from 138 percent up to 400 percent of the federal poverty level (KFF, 2015b). The ACA eliminated medical underwriting and imposed a legal mandate to purchase health insurance with a penalty for those who did not comply. Before the ACA, insurance companies used medical underwriting to determine whether to offer a person coverage, at what price, and with what exclusions or limits based on the person's health status; the purpose was to ensure a healthy risk pool by requiring people to pay premiums that reflected their expected medical costs. Because of medical underwriting in the individual and small-group markets, people who were sick often paid higher premiums or were denied coverage. The ACA's individual mandate, in contrast, was designed to compel healthier people to purchase insurance so as to balance the risk pool and lower premiums for everyone. States could establish their own health insurance exchanges or use the one created by the federal government. However, access to care (except for increases in insurance coverage) did not show improvement until the time period between 2014 and June 2017 (KFF, 2017c).

THE HEALTH-CARE DELIVERY SYSTEM BEFORE THE PATIENT PROTECTION AND AFFORDABLE CARE ACT

The health-care delivery system in the United States consists of an array of clinicians, hospitals and other health-care facilities, insurance plans, and purchasers of health-care services, all operating in various configurations of groups, networks, and independent practices (IOM, 2003). The health-care delivery system has historically been organized around the concept of fee-for-service medicine. Under the fee-for-service payment model, patients (or their insurers) pay physicians and hospitals for any covered services delivered on a per-unit basis without particular regard for price, patient outcomes, or quality. Because provider revenues increase as more services are provided—and insured (and some uninsured) patients do not bear the full cost of the additional services—the fee-for-service model creates incentives to increase utilization of health-care services, which in many cases lead to overutilization of physician and hospital visits.

In some segments of the market, health plans have been designed around alternative incentive structures by using a concept of fixed payment for a set of services. Often called managed care, these plans aim to reduce overutilization of hospital and physician services through such arrangements as full-risk capitation payment models (which involve sharing of financial risk among all participants and place providers at risk not only for their own financial performance but also for the performance of other providers in the network), some forms of bundled payment (in which a single payment covers a hospital stay or all services related to a specific diagnosis or procedure), and a more modest approach called pay-for-value (an incentive structure that includes bonuses or penalties that are based on cost and quality metrics). Managed care is intended to reduce low-value spending through better "management" of care, but concerns have been raised about stinting and rationing in which high-cost–high-need patients are

not provided with care that is expensive but necessary. Pay-for-value managed-care arrangements are used in Medicare Advantage, Medicaid managed care, and some commercial health insurance plans.

In the Medicare program, around 30 percent of beneficiaries are enrolled in Medicare Advantage plans in which Medicare makes payments to private insurers that are responsible for delivering the Medicare benefit package, and payment arrangements between plans and providers are determined contractually and are thus difficult to describe because they are proprietary (KFF, 2017a).

In sharp contrast with Medicare, managed-care enrollment has greatly expanded during the past two decades, rising from just over one-half of all beneficiaries enrolled in managed care in 2000 to 77 percent in 2014 (KFF, 2014). Medicaid-managed care plans cover a broad array of Medicaid benefits, including acute, primary, and specialty care and in some states, behavioral health and LTSS (CMS, 2016).

Although the fee-for-service model remains the most common payment form in the private health insurance market, private insurers have integrated aspects of the managed-care model into broader efforts to address the incentive problems created by the fee-for-service payment structure, such as utilization management and performance metrics for providers. If managed care is defined by the use of capitated payments to providers that are responsible for the total cost of care, then very few people are covered by managed care (KFF, 2016b). If, however, anything other than unconstrained fee-for-service is defined as managed care, most people who are covered by private health insurance are enrolled in some form of managed care. Managed care in any form usually involves restricting the set of providers from whom patients might obtain covered care to so-called in-network providers. Insurers can adjust network breadth to limit patient access to preferred hospitals and physicians. Figure 3-3 illustrates that dramatic shift over time. In 1998, 73 percent of employees enrolled in health plans had conventional fee-for-service coverage; by 2017, fewer than 1 percent had unconstrained fee-for-service coverage. The figure also shows the dramatic growth in HDHPs since 2006.
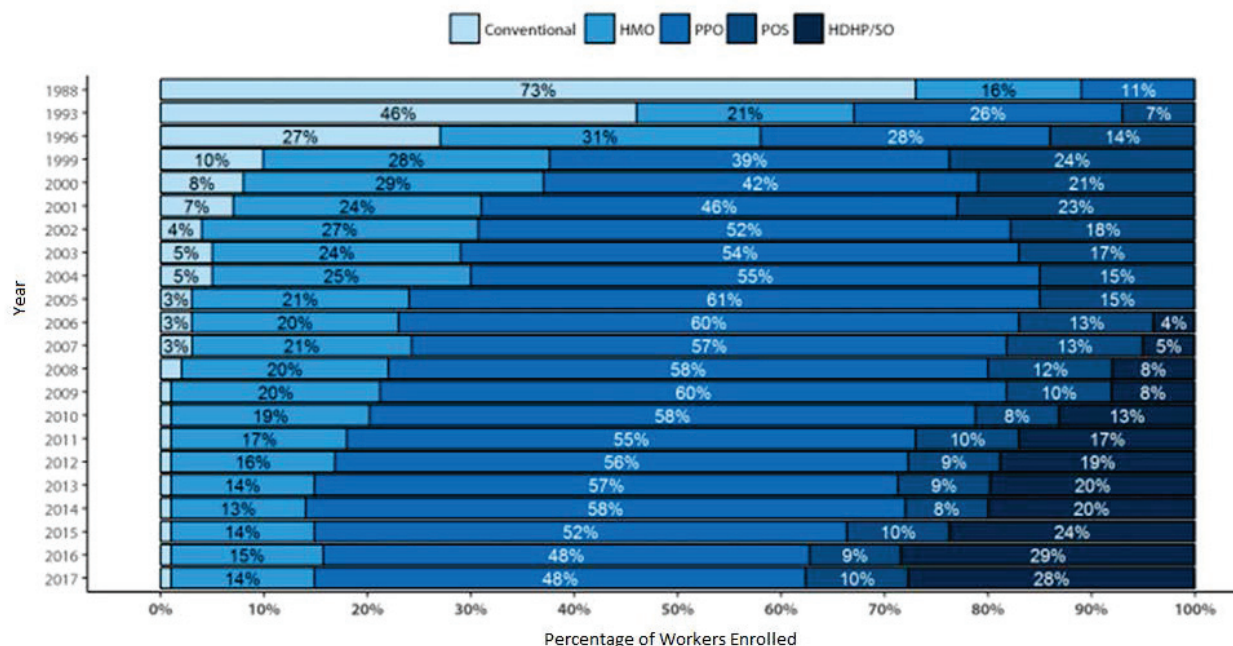
FIGURE 3-3 Distribution of health plan enrollment of covered workers, by plan type, 1988–2017.
NOTES: Information was not obtained for POS plans in 1988 or for HDHP/SO plans until 2006. A portion of the change in plan type enrollment for 2005 is likely attributable to incorporating more recent Census Bureau estimates of the number of state and local government workers and removing federal workers from the weights. See the Survey Design and Methods section from the 2005 Kaiser/HRET Survey of Employer-Sponsored Health Benefits for additional information.
SOURCE: KFF, 2017d.

HOW THE PATIENT PROTECTION AND AFFORDABLE CARE ACT CHANGED THE HEALTH-CARE DELIVERY SYSTEM

The ACA included payment-reform provisions to incentivize the adoption of more effective care-delivery models (Abrams et al., 2015). The new models involve some combination of shared risk among providers to enhance collaboration and coordination of care so as to reduce avoidable hospitalizations, ED visits, and other forms of expensive or unnecessary care. To protect against stinting, quality metrics are often used to evaluate provider performance. Beyond payment models, the ACA encouraged (perhaps unintentionally) the narrowing of provider networks and reshaped the delivery of long-term services and supports, all of which have implications for the ways in which people who have disabilities receive care and for the documentation of that care in the medical record. Also relevant is the Health Information Technology for Economic and Clinical Health (HITECH) Act, which was enacted as part of the American Recovery and Reinvestment Act (ARRA) of 2009 and incentivized investments in electronic medical records (EMRs). We discuss each in turn.

New Payment and Delivery Models

One approach to payment reform under the ACA is "bundled payment," whereby an insurer makes a single payment to a group of providers for *all* services that might be provided to a patient for a given medical condition or procedure. The payment, contractually determined in

advance, is intended to encourage better coordination among the various providers involved in a given patient's care. Some 7,000 post-acute care providers, hospitals, and physician organizations have signed up to participate in bundled-payment demonstrations (Abrams et al., 2015). Early evidence suggests that bundled payments can reduce medical costs and improve patient satisfaction (CMS, 2017).

The ACA also incentivized the development of alternative delivery models, such as accountable care organizations. Those involve collaboration among physicians, hospitals, and other health-care entities in a shared-risk arrangement. The alternative delivery models were intended to encourage provider organizations to address patient health needs better, to reduce the amount of hospital and ED care, and to meet quality goals. Their effectiveness and their effects on clinical practice, however, are still matters of considerable debate (Schulman and Richman, 2016; Song and Fisher, 2016).

Another version of health-care delivery promoted by the ACA is the patient-centered medical home (PCMH). The primary goal of the PCMH is to keep people ambulatory in the community, in addition to aligning provider financial incentives with the best interests of patients. The PCMH is not a physical home but rather a care delivery system in which each patient's care is coordinated through his or her primary care physician (PCP). The PCP manages and coordinates care with the goals of having each patient receive the necessary care when and where he or she needs it, and in a manner that the patient can understand and that is consistent with and respectful of the patient's preferences, needs, and values (Blumenthal et al., 2015). In patient-centered models, there is greater potential for providers to identify people who have comorbidities and to coordinate their care. The National Committee for Quality Assurance (NCQA) reported in 2015 that PCMHs cut the growth in outpatient ED visits by 11 percent compared with non-PCMHs among Medicare patients. Visits for both ambulatory care sensitive and non-ambulatory care sensitive conditions were reduced; this suggests that steps taken by practices to attain PCMH recognition might decrease some of the demand for outpatient ED care (van Hasselt et al., 2015). NCQA also noted that PCMH recognition is associated with fewer inpatient hospitalizations and lower utilization of both specialist and emergency services (Harbrecht and Latts, 2012; Raskas et al., 2012).

Expanding Electronic Medical Records

The HITECH Act, enacted as part of the ARRA, encouraged the adoption of health technology in the form of EMRs. Money was offered to physician practices to meet compliance with health information technology or so-called meaningful use criteria or face penalties in Medicare reimbursement. EMRs offer the promise of aggregating records from many providers into a single, legible medical record as long as all providers seen by a patient participate in the same EMR system; interoperability among systems is imperfect. The HITECH Act offers the promise of a more complete medical record that details the full history of care provided to a patient who applies for disability benefits. But it is important to note that the Social Security Administration (SSA) listings are not structured to mirror how doctors use EMRs.

Narrowing Provider Networks

The change in provider network size is another indicator of how the ACA has transformed the care that people get. So-called narrow networks existed before the implementation of the ACA, but they have grown more common as a result of it. Many

consumer protection measures, such as the prohibition of medical underwriting, have made it difficult for many insurers to rely on traditional strategies to keep costs low. Other elements of the law, such as the availability of the online marketplace where consumers can compare premiums, have made it possible for insurers to compete with each other. Plans that have narrow networks might benefit consumers by lowering premiums. Negotiations between insurers and providers on network participation might encourage more efficient delivery of care. And the ability to contract selectively might allow insurers to attract a small group of providers that meet raised standards of quality and potentially would result in care of higher value (Health Affairs, 2016).

But narrow networks also pose risks to consumers. For example, if a network gets too narrow, it will jeopardize the ability of consumers to obtain needed care in a timely manner. That can also happen if the network contains an unsatisfactory mix or insufficient number of providers. Network limitations can have the additional effect of turning away sicker patients who have more health needs and thus changing the risk pool. One study notes that consumer advocates argue that narrow networks adversely affect access to care, especially for patients who have chronic illnesses. They claim that insurers structure the networks strategically to discourage the higher-cost patients from enrolling. Patients who have high needs will then have to go outside the network (and possibly outside the EMR system) and as a result tend to incur high expenses and receive surprise medical bills (EBRI, 2016). Their medical documentation is also more likely to be missing elements.

Reshaping Long-Term Care Services and Supports

The ACA included several provisions aimed at improving deficiencies in the nation's long-term care system to ensure that people can receive LTSS in their home or the community (KFF, 2015a). In particular, the ACA expanded options for funding Medicaid home- and community-based services (HCBS). They include the Money Follows the Person Demonstration, the Balancing Incentive Program, the Section 1915(i) HCBS state plan option, and the Section 1915(k) Community First Choice state plan option. Those options have brought about a considerable increase in funds for Medicaid LTSS in the form of HCBS over the past two decades. HBSC increased from 53 percent of total Medicaid LTSS in FY 2014 to 55 percent in FY 2015 (Eiken et al., 2017).

In addition, in states that accepted the Medicaid expansion, funds were made available to pay for home- and community-based attendant services in connection with matching by the federal government (KFF, 2015a). Nonetheless, Wiener (2013) has argued that despite the growing need for HCBS, not enough progress had been made in improving the financing of long-term care. In particular, the Community Living Assistance Services and Supports (CLASS) Act under the ACA[5] failed, making home-based LTSS insurance an expensive service that was out of reach for many Americans.

---

[5]The Community Living Assistance Services and Supports Act (or CLASS Act) was a US federal law, enacted as Title VIII of the Patient Protection and Affordable Care Act. The CLASS Act would have created a voluntary and public long-term care insurance option for employees, but in October 2011 the Obama administration announced it was unworkable and would be dropped. The CLASS Act was repealed on January 1, 2013.

EFFECT OF THE PATIENT PROTECTION AND AFFORDABLE CARE ACT ON HEALTH-CARE UTILIZATION

A comprehensive review of the literature on the effects of the ACA Medicaid expansion on health-care use (KFF, 2017c) found that health insurance coverage has expanded overall, access to and use of care have increased, self-reported health status has improved, and flow of federal health-care resources into expansion states has risen.

It is less clear whether the ACA has altered utilization of EDs and hospitals. One study by Barakat et al. (2017) observed a substantial shift in payers for ED visits and hospitalizations after Medicaid expansion in California. It did not, however, detect a substantial change in top diagnoses or in the overall rate of ED visits and hospitalizations. The authors argued that there appeared to be a shift in reimbursement burden from patients and hospitals to the government without a dramatic shift in patterns of ED or hospital utilization. In contrast, Sommers et al. (2016) found that ED visits decreased and outpatient visits increased in Arkansas, Kentucky, and Texas after the ACA Medicaid expansion. Wherry and Miller (2016) observed an increase in office visits to physicians but also an increase in overnight hospital stays after the Medicaid expansion. Chen et al. (2016) noted that such minorities as blacks and Latinos, who were most affected by the ACA, experienced an even higher increase in care utilization than other groups.

There is consensus among studies on the effects of the ACA on utilization of preventive services. Sommers et al. (2016) found that use of preventive care, such as diabetes screening, increased. Similarly, Wherry and Miller (2016) found that Medicaid expansion under the ACA led to higher rates of preventive services, which resulted in more diagnoses of diabetes and high cholesterol.

Several studies have specifically identified ACA-related improvements in health-care utilization by people who had chronic conditions. Sommers et al. (2017a) examined changes in health-care use and self-reported health 3 years after the implementation of the ACA's coverage expansion among people who had chronic conditions and had been uninsured but gained coverage. They found improvements in multiple measures: affordability of care, regular care for the chronic conditions, medication adherence, and self-reported health. A related study by Sommers et al. (2016) assessed changes in access to care, utilization, and self-reported health among low-income adults in three states that took alternative approaches to the ACA implementation. They echoed the findings in the 2017 report by suggesting that regular care for chronic conditions increased substantially after Medicaid expansion. The findings of those two studies were consistent with the findings of an earlier study by Sommers et al. (2015) that detected increases in self-reported health and functional status under the ACA in people who had chronic medical conditions.

Although evidence suggests that on average people who had chronic conditions experienced an increase in access to regular care for those conditions, coverage effects vary among diseases (Baicker et al., 2013), particularly as some states were much stricter in their underwriting regulations prior to the ACA. Because of the many design features that are common to the ACA, the Massachusetts health-care reform of 2006, and the Oregon Medicaid lottery of 2008, the experiences of Massachusetts and Oregon are informative about potential effects, and in particular long-term effects, of the ACA on utilization. A study by Cole et al. (2017) examined the random assignment embedded in the Oregon Medicaid lottery and found a greater probability of a diagnosis of diabetes and the use of medications for diabetes. It found no effect of Medicaid coverage on diagnoses or on the use of medication for blood pressure and

high cholesterol, but Cole et al. (2017), in a study of the ACA's Medicaid expansion, found that coverage expansion was associated with better blood pressure control in community health center patients. The Oregon Medicaid study (Baicker et al., 2013) found substantial improvements in rates of diagnosis of and treatment for depression, which is strongly associated with disability.

The evidence on cancer care is also mixed. One study of the Massachusetts health-care reform did not find any changes in breast-cancer stage at diagnosis (Keating et al., 2013), but another found that the ACA's dependent-coverage provision was associated with earlier-stage diagnosis of and treatment for cervical cancer, particularly in young women (Robbins et al., 2015). A third study of the Massachusetts reform echoed the improvement in cancer care by revealing that coverage expansion was associated with an increase in rates of treatment for colon cancer in low-income patients and a reduction in the number of patients waiting until the emergency stage for treatment (Loehrer et al., 2016).

In addition to health-care service utilization, the use of prescription drugs serves as an important measure of the ACA's effect, especially given their prominent role in the management of chronic conditions. Mulcahy et al. (2016) found that those who had chronic conditions and gained insurance under the ACA filled an average of 28 percent more prescriptions and had a 29 percent reduction in out-of-pocket spending per prescription in 2014 compared with 2013. They attributed the increase in treatment rates for chronic conditions and the reduction in out-of-pocket spending to the decrease in financial barriers to care under the ACA. Sommers et al. (2017b) found that the first 15 months of expansion saw an increase in medication prescription rates, with the greatest increase seen in prescriptions for chronic conditions.

EFFECT OF THE PATIENT PROTECTION AND AFFORDABLE CARE ACT ON PEOPLE WITH DISABILITIES

The ACA has many provisions that are important for people who have disabilities. For example, denial of coverage because of pre-existing conditions is no longer allowed. Removal of a lifetime cap on benefits will enable people with disabilities to continue to receive care. Perhaps most important, the expansion of health insurance coverage through the Medicaid program, the health insurance exchanges, and the dependent coverage provision will allow many Americans who have disabilities to obtain health insurance coverage without having to qualify for SSDI or SSI. Those who qualify for Medicaid will have access to coverage for LTSS. And the ACA authorizes federally conducted or supported studies to collect standard demographic characteristics that include disability status (Krahn et al., 2015). In this section, we summarize the early literature on those effects.

The ACA's dependent coverage provision appears to have benefited young adults who have disabilities. Porterfield and Huang (2016) analyzed the periods before and after implementation of the dependent coverage provision in the ACA and compared adults who had disabilities and were 19–25 years old with adults who had disabilities and were 26–34 years old. People in both age groups experienced coverage gains after the ACA dependent coverage provision took effect in 2010, but for people in the older group who were unaffected by the dependent coverage provision, the coverage gains were entirely attributable to changes in *public* insurance. In contrast, the coverage gains for people in the younger group who were affected by the dependent coverage provision were driven by changes in *private* insurance.

Sommers et al. (2014) found that an early Medicaid expansion in Connecticut resulted in substantially greater coverage gains for adults who had disabilities than for adults who did not. By 2014, low-income and moderate-income nonelderly adults—including both those who had and those who did not have chronic illnesses—also experienced coverage gains. The Kaiser Family Foundation (KFF, 2017c) notes that in some states and the District of Columbia, those gains resulted from the Medicaid expansion to adults who had incomes up to 138 percent of the federal poverty level. In other states and the District of Columbia, the coverage gains for people who had disabilities resulted from subsidies for qualified health plans offered on the health insurance marketplaces combined with private insurance reforms, such as the prohibition of discrimination based on health status.

The ACA appears to have brought about improvements in treatment for mental disorders and substance abuse. Saloner and LeCook (2014) examined the effect of the ACA on young adults who had mental health or substance-use disorders by using data from the 2008–2012 National Survey of Drug Use and Health. The authors found that after implementation of the ACA, mental health treatment of people who were 18–25 years old and had possible mental health disorders increased by 5.3 percent relative to that of a comparison group of similar people who were 26–35 years old. Uninsured visits by people who used mental health treatment decreased by 12.4 percent (the ACA helps by expanding mental health services, an ACA provision). Consistent with those findings, Ali et al. (2016) estimated that the ACA could make it possible for as many as 2.8 million adults to receive behavioral health treatment through the Medicaid expansions and another 3.1 million through participation in health insurance exchanges. If those possibilities are fully realized, that would represent a 40 percent increase in behavioral services utilization, primarily for mental health services. Golberstein et al. (2015) similarly found that the ACA's dependent coverage provisions produced increases in general hospital psychiatric inpatient admissions, for substance use disorders and non-substance use psychiatric conditions, and higher rates of insurance coverage for young adults nationally, with the exception of visits to the ED in California.

A recent study (Hall et al., 2017) examined the effect of the Medicaid expansion on workforce participation by people who have disabilities. The authors noted that people who have disabilities often experience psychologic distress and comorbid health conditions and have low income and employment. New coverage options under Medicaid expansion that allow people to work more and accumulate assets could benefit people who have disabilities because they would no longer need to apply for SSI or live in poverty to qualify for Medicaid. Results from the Hall et al. study indicated that the number of adults who had disabilities and were employed increased in expansion states and decreased in nonexpansion states. Those changes were not statistically significant, because of the small sample in the pre-ACA period. However, after the ACA, those who had disabilities and lived in expansion states were more likely to be employed (38.0 percent versus 31.9 percent) and less likely to be unemployed than those who lived in nonexpansion states. The authors concluded that Medicaid expansion is an important policy for reducing disparities in access to care for people who have disabilities and for supporting their employment and financial independence.

Despite the many positive benefits of the ACA, there remain barriers to access to care among people who have disabilities. Among them is the complexity of the Medicaid application process (Gettens and Adams, 2015). Cost-related difficulties present another barrier. Despite the ACA's subsidies for qualified health plans, which have reduced premium costs to some degree, deductibles and other out-of-pocket costs remain high and pose financial challenges to many

people who have disabilities (Gettens and Adams, 2015). A third concern related to the implementation of the ACA Medicaid expansion has been difficulties with respect to LTSS.

SUMMARY AND CONCLUSIONS

Health care in the United States is financed by a combination of public and private insurance, employers, and out-of-pocket payments by individuals. In 2015, 37 percent of the US population received health care through a public insurance program at some point during the year. The major public insurance systems are Medicare and Medicaid. In 2016, Medicare benefit payments totaled $675 billion and accounted for 15 percent of the federal budget.

The US health-care delivery system consists of an array of clinicians, hospitals and other health-care facilities, insurance plans, and purchasers of health-care services, all of which operate in various configurations of groups, networks, and independent practices. The health-care delivery system historically has been organized around the concept of fee-for-service medicine. Under the fee-for-service payment model, patients (or their insurers) pay physicians and hospitals for any covered services delivered on a per-unit basis without particular regard for price, patient outcomes, or quality. Because provider revenues increase as more services are provided—and insured (and some uninsured) patients do not bear the full cost of the services—the fee-for-service model creates incentives to increase utilization of health-care services and leads in many cases to overutilization of physician and hospital visits.

The ACA was the largest federal health policy initiative since the creation of Medicare and Medicaid. It brought about structural changes in the health-care system, which included sweeping efforts to improve access to health insurance through expansion of the Medicaid program and through subsidized and lower-cost health insurance plans made available through new health insurance marketplaces (exchanges), elimination of pre-existing condition restrictions on coverage, elimination of lifetime caps on health-care spending, and efforts to slow growth in health-care costs through innovative payment reforms.

A major goal of the ACA was to extend health insurance coverage to 32 million uninsured people in the United States. The plan had two major components: expansion of the Medicaid program and new structures to support the individual and small-group health insurance markets. The ACA eliminated the concept of categorical eligibility and replaced it with standard eligibility criteria of 138 percent of the federal poverty level. In 2012, the Supreme Court ruled that the federal government could not force the states to expand Medicaid coverage. As a result, only 32 states and the District of Columbia elected to expand Medicaid.

For the individual and small-group markets, the ACA established health insurance exchanges in states to allow individuals and small groups to buy standard insurance policies with income-based subsidies from 138 percent to 400 percent of the federal poverty level. The ACA eliminated medical underwriting and imposed a legal mandate to purchase health insurance, with a penalty for those who did not comply. The ACA's individual mandate was designed to compel healthier people to purchase insurance and thereby balance the risk pool and lower premiums for everyone.

The ACA included payment-reform provisions to incentivize the adoption of more effective care delivery models. The new models involve some combination of shared risk among providers to enhance collaboration and coordination of care in an effort to reduce avoidable hospitalizations, ED visits, and other forms of expensive or unnecessary care. To protect against stinting, quality metrics are often used to evaluate provider performance. Beyond payment

models, the ACA encouraged (perhaps unintentionally) the narrowing of provider networks and reshaped the delivery of LTSS, all of which have implications for how people who have disabilities receive care and the documentation of that care in the medical record.

The ACA has many provisions that are important for people who have disabilities. For example, denial of coverage because of pre-existing conditions is no longer allowed. The expansion of health insurance coverage through the Medicaid program, the health insurance exchanges, and the dependent coverage provision will allow many Americans who have disabilities to obtain health insurance coverage without having to qualify also for SSDI or SSI. Those who qualify for Medicaid will have access to coverage for LTSS.

A comprehensive review of the literature on the effects of the ACA Medicaid expansion on health-care use finds that health insurance coverage overall has expanded, access and use of care have increased, self-reported health status has improved, and the flow of federal health-care resources into expansion states has risen. It is less clear whether the ACA has altered utilization of EDs and hospitals.

REFERENCES

Abrams, M. K., R. Nuzum, M. A. Zezza, J. Ryan, J. Kiszla, and S. Guterman. 2015. *The Affordable Care Act's payment and delivery system reforms: A progress report at five years.* New York: The Commonwealth Fund.

Ali, M. M., J. Teich, A. Woodward, and B. Han. 2016. The implications of the Affordable Care Act for behavioral health services utilization. *Administration and Policy in Mental Health and Mental Health Services Research* 43(1):11–22.

American College of Emergency Physicians. 2016. *EMTALA: Main points.* https://www.acep.org/News-Media-top-banner/EMTALA (accessed November 7, 2017).

Baicker, K., S. L. Taubman, H. L. Allen, M. Bernstein, J. H. Gruber, J. P. Newhouse, E. C. Schneider, B. J. Wright, A. M. Zaslavsky, A. N. Finkelstein, and G. Oregon Health Study. 2013. The Oregon experiment—effects of Medicaid on clinical outcomes. *New England Journal of Medicine* 368(18):1713–1722.

Barakat, M. T., A. Mithal, R. J. Huang, A. Mithal, A. Sehgal, S. Banerjee, and G. Singh. 2017. Affordable Care Act and healthcare delivery: A comparison of California and Florida hospitals and emergency departments. *PLoS ONE* 12(8):e0182346.

Blumenthal, D., M. Abrams, and R. Nuzum. 2015. The Affordable Care Act at 5 years. *New England Journal of Medicine* 372(25):2451–2458.

Brot-Goldberg, Z. C., A. Chandra, B. R. Handel, and J. T. Kolstad. 2017. What does a deductible do? The impact of cost-sharing on health care prices, quantities, and spending dynamics. *The Quarterly Journal of Economics* 132(3):1261–1318.

CBO (Congressional Budget Office). 2014. *Veterans' disability compensation: Trends and policy options.* Washington, DC: CBO. https://www.cbo.gov/publication/45615 (accessed November 7, 2017).

CMS (Centers for Medicare & Medicaid Services). 2012. *Emergency Medical Treatment and Labor Act (EMTALA).* https://www.cms.gov/Regulations-and-Guidance/Legislation/EMTALA/index.html (accessed November 7, 2017).

CMS. 2016. *Medicaid managed care enrollment and program characteristics, 2014.* Baltimore, MD: CMS. https://www.medicaid.gov/medicaid-chip-program-information/by-topics/data-and-systems/medicaid-managed-care/downloads/2014-medicaid-managed-care-enrollment-report.pdf (accessed November 7, 2017).

CMS. 2017. *Bundled Payments for Care Improvement (BCPI) initiative: General information.* https://innovation.cms.gov/initiatives/bundled-payments (accessed November 7, 2017).

Cole, M. B., O. Galarraga, I. B. Wilson, B. Wright, and A. N. Trivedi. 2017. At federally funded health centers, Medicaid expansion was associated with improved quality of care. *Health Affairs (Millwood)* 36(1):40–48.

EBRI (Employee Benefit Research Institute). 2016. *Issue brief no. 428: Narrow provider networks for employer plans.* Washington, DC: EBRI. https://www.ebri.org/publications/ib/index.cfm?fa=ibDisp&content_id=3404 (accessed November 7, 2017).

Eiken, S., K. Sredl, B. Burwell, and R. Woodward. 2017. *Medicaid expenditures for long-term services and supports (LTSS) in FY 2015.* Truven Health Analytics. Bethesda, MD. https://www.medicaid.gov/medicaid/ltss/downloads/reports-and-evaluations/ltssexpendituresffy2015final.pdf (acessed February 5, 2018).

Gettens, J., and A. Adams. 2015. Assessing health care reform: Changes to reduce the complexity of the application process for individuals with disabilities. *Journal of Disability Policy Studies* 27(1):22–31.

Golberstein, E., S. H. Busch, R. Zaha, S. F. Greenfield, W. R. Beardslee, and E. Meara. 2015. Effect of the Affordable Care Act's young adult insurance expansions on hospital-based mental health care. *American Journal of Psychiatry* 172(2):182-189.

Hall, J. P., A. Shartzer, N. K. Kurth, and K. C. Thomas. 2017. Effect of Medicaid expansion on workforce participation for people with disabilities. *American Journal of Public Health* 107(2):262–264.

Harbrecht, M. G., and L. M. Latts. 2012. Colorado's patient-centered medical home pilot met numerous obstacles, yet saw results such as reduced hospital admissions. *Health Affairs (Millwood)* 31(9):2010–2017.

Health Affairs. 2016. *Health Affairs health policy brief: Regulation of health plan provider networks.* Bethesda, MD: Health Affairs. https://www.healthaffairs.org/do/10.1377/hpb20160728.898461/full (accessed February 5, 2018).

IOM (Institute of Medicine). 2003. *The future of the public's health in the 21st century.* Washington, DC: The National Academies Press.

Keating, N. L., E. M. Kouri, Y. He, D. W. West, and E. P. Winer. 2013. Effect of Massachusetts health insurance reform on mammography use and breast cancer stage at diagnosis. *Cancer* 119(2):250–258.

KFF (Kaiser Family Foundation). 2014. *Total Medicaid managed care enrollment.* https://www.kff.org/medicaid/state-indicator/total-medicaid-mc-enrollment (accessed November 7, 2017).

KFF. 2015a. *Medicaid and long-term services and supports: A primer.* Washington, DC: KFF. https://www.kff.org/medicaid/report/medicaid-and-long-term-services-and-supports-a-primer/view/footnotes (accessed November 7, 2017).

KFF. 2015b. *The coverage provisions in the Affordable Care Act: An update.* http://files.kff.org/attachment/issue-brief-the-coverage-provisions-in-the-affordable-care-act-an-update (accessed November 7, 2017).

KFF. 2016a. *Total Medicaid spending FY 2016.* https://www.kff.org/medicaid/state-indicator/total-medicaid-spending (accessed November 7, 2017).

KFF. 2016b. *2016 employer health benefits survey.* https://www.kff.org/report-section/ehbs-2016-summary-of-findings (accessed November 7, 2017).

KFF. 2016c. *Explaining health care reform: Risk adjustment, reinsurance, and risk corridors.* https://www.kff.org/health-reform/issue-brief/explaining-health-care-reform-risk-adjustment-reinsurance-and-risk-corridors (accessed November 7, 2017).

KFF. 2017a. *The facts on Medicare spending and financing.* https://www.kff.org/medicare/issue-brief/the-facts-on-medicare-spending-and-financing (accessed November 7, 2017).

KFF. 2017b. *Status of state action on the Medicaid expansion decision.* https://www.kff.org/health-reform/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act (accessed November 7, 2017).

KFF. 2017c. *The effects of Medicaid expansion under the ACA: Updated findings from a literature review.* Washington, DC: KFF. https://www.kff.org/medicaid/issue-brief/the-effects-of-medicaid-expansion-under-the-aca-updated-findings-from-a-literature-review-september-2017 (accessed November 7, 2017).

KFF. 2017d. *2017 employer health benefits survey.* https://www.kff.org/report-section/ehbs-2017-section-5-market-shares-of-health-plans (accessed November 7, 2017).

Krahn, G. L., D. K. Walker, and R. Correa-De-Araujo. 2015. Persons with disabilities as an unrecognized health disparity population. *American Journal of Public Health* 105(Suppl 2):S198–S206.

Loehrer, A. P., Z. Song, A. B. Haynes, D. C. Chang, M. M. Hutter, and J. T. Mullen. 2016. Impact of health insurance expansion on the treatment of colorectal cancer. *Journal of Clinical Oncology.* 34(34):4110-4115.

Mulcahy, A. W., C. Eibner, and K. Finegold. 2016. Gaining coverage through Medicaid or private insurance increased prescription use and lowered out-of-pocket spending. *Health Affairs (Millwood)* 35(9):1725–1733.

Porterfield, S. L., and J. Huang. 2016. Affordable Care Act provision had similar, positive impacts for young adults with and without disabilities. *Health Affairs* 35(5):873–879.

Raskas, R. S., L. M. Latts, J. R. Hummel, D. Wenners, H. Levine, and S. R. Nussbaum. 2012. Early results show WellPoint's patient-centered medical home pilots have met some goals for costs, utilization, and quality. *Health Affairs (Millwood)* 31(9):2002–2009.

Robbins, A. S., X. Han, E. M. Ward, E. P. Simard, Z. Zheng, and A. Jemal. 2015. Association between the Affordable Care Act dependent coverage expansion and cervical cancer stage and treatment in young women. *JAMA* 314(20):2189–2191.

Saloner, B., and B. Le Cook. 2014. An ACA provision increased treatment for young adults with possible mental illnesses relative to comparison group. *Health Affairs (Millwood)* 33(8):1425–1434.

Schulman, K. A., and B. D. Richman. 2016. Reassessing ACOS and health care reform. *JAMA* 316(7):707–708.

Sommers, B. D., G. M. Kenney, and A. M. Epstein. 2014. New evidence on the Affordable Care Act: Coverage impacts of early Medicaid expansions. *Health Affairs (Millwood)* 33(1):78–87.

Sommers, B. D., M. Z. Gunja, K. Finegold, and T. Musco. 2015. Changes in self-reported insurance coverage, access to care, and health under the Affordable Care Act. *JAMA* 314(4):366–374.

Sommers, B. D., R. J. Blendon, E. J. Orav, and A. M. Epstein. 2016. Changes in utilization and health among low-income adults after Medicaid expansion or expanded private insurance. *JAMA Internal Medicine* 176(10):1501–1509.

Sommers, B. D., B. Maylone, R. J. Blendon, E. J. Orav, and A. M. Epstein. 2017a. Three-year impacts of the Affordable Care Act: Improved medical care and health among low-income adults. *Health Affairs (Millwood)* 36(6):1119–1128.

Sommers, B. D., A. A. Gawande, and K. Baicker. 2017b. Health insurance coverage and health–what the recent evidence tells us. *New England Journal of Medicine* 377(6):586–593.

Song, Z., and E. S. Fisher. 2016. The ACO experiment in infancy—looking back and looking forward. *JAMA* 316(7):705–706.

USCB (US Census Bureau). 2016. Health insurance coverage in the United States: 2015. In *Current Population Reports.* Washington, DC: US Government Printing Office. https://www.census.gov/content/dam/Census/library/publications/2016/demo/p60-257.pdf (accessed November 7, 2017).

van Hasselt, M., N. McCall, V. Keyes, S. G. Wensky, and K. W. Smith. 2015. Total cost of care lower among Medicare fee-for-service beneficiaries receiving care from patient-centered medical homes. *Health Services Research Journal* 50(1):253–272.

Wherry, L. R., and S. Miller. 2016. Early coverage, access, utilization, and health effects associated with the Affordable Care Act Medicaid expansions: A quasi-experimental study. *Annals of Internal Medicine* 164(12):795–803.

Wiener, J. M. 2013. After class: The Long-Term Care Commission's search for a solution. *Health Affairs (Millwood)* 32(5):831–834.

4

Health-Care Utilizations as Proxies
for Listing-Level Severity

This chapter examines health-care utilizations for particular medical conditions and how they might be related to impairment severity and disability. Chapter 2 described the many factors associated with health-care utilization. This chapter describes what is known about how utilization might be associated with the ability to work and the many confounding factors that make this association difficult to measure. It examines the feasibility of using utilization measures other than the ones currently in use in the determination process. For each body system that appears in the Social Security Administration (SSA) Listing of Impairments, the chapter focuses on the following elements of the committee's statement of task on the basis of available data:

- Explain how types of utilizations are more or less probable for particular medical conditions or combinations of medical conditions.
- Identify health-care utilizations that represent and are good indicators of impairment severity.
- Explain how intervals between utilizations and duration of utilizations affect whether health-care utilization is a good indicator of impairment severity.

Finally, the committee briefly discusses how health-care utilizations might interfere with the ability to work.

DEFINITIONS

The committee's task is to analyze the relationship of health-care utilizations to "impairment severity" and "SSA's definition of disability," so it is important to define these terms. SSA defines a severe impairment as one that "significantly limits an individual's physical or mental abilities to do basic work activities" (SSR 96-3p); according to the committee's statement of task, "listing-level" severity refers to an impairment that is "severe enough to prevent a person from doing any gainful activity." SSA defines disability as "the inability to engage in any substantial gainful activity (SGA) by reason of any medically determinable physical or mental impairment(s) which can be expected to result in death or which has lasted or

can be expected to last for a continuous period of not less than 12 months"[1] (SSA, 2017a). SSA thus defines severe impairment and disability similarly, the difference being the extent of a person's inability to perform over some period, that is, to perform any gainful activity in the case of severe impairment as opposed to performing substantial gainful activity in the case of disability.[2]

Other organizations define the terms differently. Although the committee's statement of task asks it to focus on SSA's definitions of the terms because the body of evidence that links health-care utilizations with inability to perform any or substantial gainful activity is small, the committee did not limit its search to these definitions. It also considered related concepts, such as disease severity and impairment, according to definitions used by other authoritative bodies.

Disease severity refers to the presence and extent of disease. It can be objectively evaluated through diagnostic testing and physiologic examination (Finlayson et al., 2004). Specific evaluation criteria might include such information as disease progression, likelihood of death, likelihood of high inpatient expenses, likelihood of length of stay, and disease burden (e.g., presence or absence of comorbidities). Other measurement schemes include stage of the disease, complications of the principal conditions, concurrent interacting conditions that affect the hospital course, dependence on hospital staff, extent of non–operating-room life-support procedures, rate of response to therapy or rate of recovery, and impairment remaining after therapy for acute aspect of the hospitalization (Horn et al., 1984).

With regard to *impairment*, the World Health Organization defines it as any loss or abnormality of psychologic, physiologic, or anatomic structure or function. According to the American Medical Association (AMA), impairment is defined as "a significant deviation, loss, or loss of use of any body structure or body function in an individual with a health condition, disorder, or disease" (AMA, 2008).

The term *impairment severity* appears in the literature primarily in the context of Social Security disability. It is also mentioned by AMA in its *Guides to the Evaluation of Permanent Impairment* (AMA, 2008) as degree of loss of body structure or function, which "can vary according to discrete (i.e., level of amputation) or continuous (i.e., degrees of motion lost) criteria." According to AMA's definition, severity of impairment is closely related to disease severity but distinct from disability, which is defined as "activity limitations and/or participation restrictions in an individual with a health condition, disorder, or disease." This distinction can be contrasted with how SSA defines both impairment severity and disability in terms of activity limitations.

DATA

Determination of disability would, in theory, require the use of longitudinal or continuing data gathered over some period to assess the continuing nature of the condition. Longitudinal event-level health-care utilization data at the person level are sparse. Even data on episodes of utilization are limited in that continuing collection of utilization data over a given period is required. (The Agency for Healthcare Research and Quality [AHRQ] Medical Expenditure Panel Survey can be used to assess episodes of care but not at the diagnosis level.) Longitudinal

---

[1] A few health-care utilizations are used by SSA as criteria in step 3 of its disability-determination process, for example, "exacerbations or complications requiring three hospitalizations within a 12-month period and at least 30 days apart."

[2] See CFR § 404.1505 for the full definition of disability.

collection of data is expensive and often involves small samples. Followup of sample respondents is often difficult. Federal data therefore tend to focus on individual events, and surveys are not granular enough to link specific utilizations with specific conditions. Analyses at the episode or person level have been conducted with Medicare or private-insurer all-payer data; there is no comparable nationally representative dataset for all working-age adults.

Because nationally representative diagnosis-specific episode or person-level data are not readily available, the committee chose to use Healthcare Cost and Utilization Project (HCUP) data to provide some insight into the relationship between specific diagnoses and health-care utilizations associated with severe illness, disease, or injury. Hospitalizations and emergency department (ED) visits generally indicate more severe illness or conditions than do ambulatory care visits. The committee tabulates ED visits and hospitalizations for selected medical conditions relevant to disability determination. It created tables by using HCUPnet, an online query system that exports user-specified descriptive statistics from HCUP data (AHRQ, 2017a). HCUP is the largest collection of longitudinal hospital care data in the United States and includes data on inpatient visits in 44 states and the District of Columbia and on ED visits in 33 states and the District of Columbia (AHRQ, 2017b). It includes data on all patients regardless of payer. ED and inpatient data are weighted national estimates of data from 2014. The committee chose to include patients 18–64 years old inasmuch as most adults who receive disability insurance are in this age range. The committee selected several *Clinical Classifications Software* (*CCS*) codes, categories developed by AHRQ that collapse the *International Classification of Diseases* (*ICD*) codes into clinically meaningful groups of diagnoses and procedures that reflect diagnoses and procedures for which people receive disability insurance.

Health-care utilization is often not associated with one specific condition. A patient might have multiple comorbid conditions but present to a medical provider for a specific symptom or problem. For each HCUP hospital or ED event, up to five diagnoses are recorded. One of them is coded as the principal, or first listed. In analyzing the data, selection of the principal diagnosis avoids duplication of events, whereas analyzing all listed diagnoses would duplicate events if several diagnoses were compared. Analyzing all listed diagnoses, however, shows the importance of comorbid conditions, as shown in Table 4-1. Among people who were 45–64 years old, there were more than 170,000 hospitalizations with a diagnosis of rheumatoid arthritis, but fewer than 5,000 of the people who had that diagnosis had rheumatoid arthritis as the principal reason for hospitalization. Similarly, among people who were 45–64 years old, there were almost 2 million hospitalizations with a diagnosis of uncomplicated diabetes mellitus, but fewer than 4,000 of them had it as the principal diagnosis. Other comorbid conditions appear to be less prevalent; of hospitalizations with a diagnosis of schizophrenia or related psychoses, about 300,000 had this diagnosis listed, and about 200,000 of them had it listed as the principal diagnosis.

As described in Chapter 2, many factors other than severity of a condition are associated with health-care utilization. Age is one such factor that is available for tabulation in the HCUP software. As shown in Table 4-1, the number of hospitalizations for many diagnoses is larger for people 45–64 years old than for younger adults. That is consistent with the increasing prevalence of several chronic conditions with age, including diabetes, hypertension and heart disease, and arthritis (NCHS, 2017a). For other diagnoses, such as mental health disorders, prevalence and associated hospitalizations do not increase with age. When a diagnosis incorporates some measure of severity, such as the diagnosis of diabetes mellitus with complications, it makes other characteristics, such as age, less important to consider. Most younger adults with a diagnosis of

diabetes mellitus with complications had it listed as the principal diagnosis. Older adults with any diagnosis of diabetes mellitus with complications were less likely than younger adults to have it listed as the principal condition; this indicates that they were more likely to be hospitalized for a comorbid condition. That the number of comorbid conditions increases with age makes the relationship of an individual health event, such as a hospitalization or ED visit, to a specific condition less straightforward. Utilization is more related to sets of conditions, but analysis of which specific conditions should be grouped is extremely complex and faces many data limitations because of limitations in the number of conditions coded for each event and the lack of person-level data on the association between multiple specific groups of comorbid conditions and outcomes.

TABLE 4-1 Hospitalizations and Emergency Department Visits for Selected Diagnoses by Age Group, 2014

	Age (years)	No. Hospitalizations (Principal Diagnosis)	No. Hospitalizations (Any Listed Diagnosis)	No. ED Visits (Principal Diagnosis)	No. ED Visits (Any Listed Diagnosis)
Rheumatoid arthritis	18–44	1,875	40,690	11,121	113,475
	45–64	4,245	174,350	15,920	261,284
Chronic obstructive pulmonary disease	18–44	15,055	123,105	428,054	800,494
	45–64	207,510	1,334,910	716,674	2,566,250
Asthma	18–44	57,365	525,900	672,021	3,207,651
	45–64	101,810	846,255	415,384	1,992,940
Congestive heart failure, nonhypertensive	18–44	36,205	154,510	46,064	258,956
	45–64	216,960	1,049,790	250,728	1,372,318
Hypertension with complications and secondary hypertension	18–44	37,920	259,940	57,126	378,421
	45–64	91,585	1,135,015	126,697	1,334,815
Gastritis and duodenitis	18–44	18,900	105,370	313,802	527,001
	45–64	28,050	214,675	146,079	388,181
Diverticulosis and diverticulitis	18–44	36,980	62,355	86,577	159,510
	45–64	108,245	268,125	196,719	455,097
Chronic renal failure	18–44	5,025	265,170	15,807	425,281
	45–64	7,840	1,113,365	26,476	1,363,201
Diabetes mellitus without complication	18–44	3,370	408,830	127,544	2,020,023
	45–64	3,940	1,864,901	154,277	4,888,412
Diabetes mellitus with complications	18–44	166,095	346,030	252,650	519,229
	45–64	208,550	1,014,680	319,224	1,201,715

Multiple sclerosis	18–44	11,635	30,030	19,381	85,898
	45–64	9,610	73,390	13,208	128,634
Schizophrenia and other psychotic disorders	18–44	197,675	303,940	411,316	805,612
	45–64	145,280	365,200	258,978	714,602
Mood disorders	18–44	405,525	1,247,305	742,179	3,331,018
	45–64	257,525	1,984,685	395,662	3,117,556
Substance-related disorders	18–44	116,880	859,670	476,782	2,209,368
	45–64	66,590	736,975	164,596	1,249,413

NOTES: This data table was produced by using HCUPnet (AHRQ, 2017a), sorting by *CCS* codes, and stratifying by age group. *CCS* codes are diagnostic categories developed by AHRQ that collapse *ICD* codes into clinically meaningful groups. ED data are weighted national estimates from the HCUP National Emergency Department Sample (NEDS), 2014, with an undefined population sample size; inpatient data are weighted national estimates from the HCUP National Inpatient Sample, 2014, N = 35,358,818.
SOURCE: AHRQ, 2017a.

Tables 4-2 and 4-3 present more detailed utilization data, showing length of hospital stays and percentages of ED visits that led to hospital admissions. They also present the rate of hospitalizations and ED visits per 100,000 people. Separate tables are presented for the populations 18–44 and 45–64 years old due to restrictions on the HCUP software, which produces hospital length of stay and rates per 100,000 people for those age groups. For these tables the principal diagnosis at admission is used because it is most strongly related to the reason for the admission or visit. These tables show the wide variation in use of hospitals and EDs for specific diagnoses and differences in severity as measured by the need for long hospital stays or for hospital admission from the ED.

TABLE 4-2 Hospitalizations and Emergency Department Visits of People 18–44 Years Old for Selected Health Conditions in the United States in 2014

	ALS	Asthma	COPD	Rheumatoid Arthritis and Related Conditions	Congestive Heart Failure, Nonhyper-tensive	Schizophrenia and Other Psychotic Disorders	Chronic Renal Failure
CCS category	*ICD 335.2*	*128*	*127*	*202*	*108*	*659*	*158*
Hospital stays							
No. hospital stays	170	57,365	15,055	1,875.0	36,205	197,675	7,840
No. hospital discharges per 100,000 people	0.1	49.7	13.0	1.6	31.3	171.2	9.4
Hospital length of stay (mean days)	4.9	3.0	4.1	4.1	5.5	9.6	4.1

ED visits

No. ED visits	174	672,021	428,054	11,121	46,064	411,316	15,807
No. ED visits per 100,000 people	0.2	581.9	370.6	9.6	39.9	356.1	13.7
Percentage admitted to hospital	56.9	8.3	2.8	10.2	70.1	40.5	NA

NOTES: ALS = amyotrophic lateral sclerosis; *CCS = Clinical Classification Software*; COPD = chronic obstructive pulmonary disease; ED = emergency department; *ICD = International Classification of Diseases*. This table was produced by using HCUPnet (AHRQ, 2017a), sorting by *CCS* codes, and stratifying by age group. ED data are weighted national estimates from the HCUP National Emergency Department Sample, 2014, with an undefined population sample size; inpatient data are weighted national estimates from the HCUP National Inpatient Sample, 2014, N = 35,358,818.
SOURCE: AHRQ, 2017a.

High rates of hospitalization for the selected diseases provide some information on the severity of the diseases if it is assumed that diagnoses with high rates are more severe and require more hospitalizations. Cardiac disease and arthritis increase with patient age, and rates per 100,000 people are higher among people 45–64 years old (see Table 4-3) than among their younger working-age counterparts (see Table 4-2). In 2016, however, about 6 percent of people who were 45–64 years old had self-reported coronary heart disease of any kind (NCHS, 2017a), and about 8 percent had asthma.

TABLE 4-3 Hospitalizations and Emergency Department Visits of People 45–64 Years Old for Selected Health Conditions in the United States in 2014

	ALS	Asthma	COPD	Rheumatoid Arthritis and Related Conditions	Congestive Heart Failure, Nonhyper-tensive	Schizophrenia and Other Psychotic Disorders	Chronic Renal Failure
CCS category	*ICD 335.2*	*128*	*127*	*202*	*108*	*659*	*158*
Hospital stays							
No. hospital stays	950	101,810	207,510	4,245	216,960	145,280	7,840
No. hospital discharges per 100,000 people	1.1	121.9	248.4	5.1	259.7	173.9	9.4
Hospital length of stay (mean days)	5.0	3.8	4.0	3.9	5.4	11.1	4.1
ED visits							
No. ED visits	1,014	415,384	716,674	15,920	250,728	258,978	26,476
No. ED visits per 100,000 people	1.2	497.2	857.9	19.1	300.1	310.0	31.7

Percentage admitted to hospital	62.7	23.1	26.6	12.3	74.4	43.6	18.8

NOTES: ALS = amyotrophic lateral sclerosis; *CCS = Clinical Classification Software*; COPD = chronic obstructive pulmonary disease; ED = emergency department; *ICD = International Classification of Diseases*. This table was produced by using HCUPnet (AHRQ, 2017a), sorting by *CCS* codes, and stratifying by age group. ED data are weighted national estimates from the HCUP National Emergency Department Sample, 2014, with an undefined population sample size; inpatient data are weighted national estimates from the HCUP National Inpatient Sample, 2014, N = 35,358,818.
SOURCE: AHRQ, 2017a.

Large percentages of ED visits for some diagnoses, such as hypertension with complications and congestive heart failure, result in hospitalization. Very few ED visits for other diagnoses, such as rheumatoid arthritis and related conditions, result in hospitalization, even when rheumatoid diagnosis is coded as the principal diagnosis. But, that information says little about the severity of a disease overall; to know that, one must also know the prevalence of the disease in the population. Asthma, for example, has a relatively high incidence per 100,000 people but is much more prevalent than congestive heart failure overall and can be controlled in most cases. Congestive heart failure is usually not diagnosed until it is serious, so rates of hospitalization after ED visits are relatively high. The data appear to show that the diagnosis is more related to the probability of a hospitalization, ED visit, or hospitalization after an ED visit than the other way around; that is, hospitalization or an ED visit is not indicative of the severity of the diagnosis.

The remainder of the chapter discusses what is known about the relationship between specific health-care utilizations and impairment severity, by organ system, and then discusses what is known about the relationship between utilization and the ability to work. The public-access SSA data do not provide statistics on particular medical conditions. Finally, this chapter summarizes the committee's findings from the literature review. The evidence review strategy is outlined in Appendix B, and the details of each study cited in this chapter can be found in Appendix C.

MUSCULOSKELETAL SYSTEM

Disorders of the musculoskeletal system accounted for 28.2 percent of diagnoses of disability insurance beneficiaries in 2014, making them the most common type of impairment among disabled workers who were awarded disability insurance payments (SSA, 2015).

Disorders and impairments of the musculoskeletal system might result from hereditary, infectious, inflammatory, neoplastic, degenerative, and traumatic processes. Musculoskeletal impairments can cause an inability to walk or perform fine or gross movements effectively on a sustained basis. Musculoskeletal disorders are the number one cause of severe long-term pain and physical disability worldwide. According to self-reported data, one-fourth of adults who were 18–64 years old had low back pain that lasted a day or more in the past 3 months (NCHS, 2017a); if other types of musculoskeletal conditions are included, the fraction is even higher. Their burden on people and health systems is expected to grow dramatically as the population ages; osteoarthritis is predicted to be the fourth-leading cause of disability in 2020 (Woolf and Pfleger, 2003).

There are ways of grading the severity of musculoskeletal disorders medically. For instance, the severity level of osteoarthritis is based on the degree of narrowing of joint spaces and the location and frequency of pain (Woolf and Pfleger, 2003).

In general, although health-care utilization might have been discussed to some extent in the research examined, its use as a proxy for impairment severity meets various barriers. One such barrier is that utilization varies with nonmedical factors, including social factors (Neumatitis et al., 2016), hospital factors (Pendleton et al., 2007), insurance (Menendez and Ring, 2015; Neumatitis et al., 2016), and economic and geographic factors (Young et al., 2009, 2015; Menendez and Ring, 2015). Much of the current research available on musculoskeletal injury and illness that lead to disability does not look at health-care utilization as a function of disability (see Appendix C). Research that includes it to any extent does not consistently note that health-care utilization increases or decreases as a function of disability.

Health-care utilizations alone are not shown to predict disease severity or disability, and other factors arose as predictive. Health-care utilizations are found to increase for nonclinical reasons not related to severity of injury or impairment, and these nonclinical factors might also drive down health-care utilization. Hence, any relationship is complex and depends on other factors that are nonclinical and might not be easily measured.

SPECIAL SENSES AND SPEECH

Disorders related to special senses and speech include visual disorders, hearing impairment, vertigo, and loss of speech. It is estimated that in 2011 uncorrectable vision loss resulted in a social burden of 283,000 disability-adjusted life-years lost. The prevalence of blindness, according to 2005–2008 National Health and Nutrition Examination Survey data, was 0.1–0.15 percent in people who were 18–64 years old (NORC, 2013). About 12 percent of people who were 45–64 years old reported being blind or having trouble seeing even with glasses in 2014 (NCHS, 2017a). Disabling hearing loss has a prevalence of 2 percent in people who are 45–54 years old; this increases to 8.5 percent in people who are 55–65 years old (NIDCD, 2016).

Various tests are used to measure the clinical severity of this group of disorders. For example, visual-acuity efficiency for best corrected vision is used to measure the severity of vision loss. There are special rules for disability insurance applicants who are blind (whose vision cannot be corrected to better than 20/200). Blind claimants might receive up to $1,950/month without their work being considered substantial gainful activity compared with a limit of $1,170/month for nonblind applicants in 2017 (SSA, 2017b). Hearing thresholds in decibels and speech-discrimination scores are used to measure hearing impairments.

Few studies have examined associations between health-care utilizations and the severity of vision loss, hearing loss, and other disorders of the special senses. The one study included in Appendix C (McKee et al., 2015) did not discuss health-care utilization with respect to impairment severity but suggested that deafness could be a comorbid condition that increases the likelihood of ED visits. The evidence does not appear to suggest any health-care utilization that is a good indicator of impairment severity in this body system.

RESPIRATORY DISORDERS

Respiratory impairments can lead to disability and severe impairment. The most common impairing respiratory diseases are asthma, chronic obstructive pulmonary disease (COPD), emphysema, interstitial fibrosis, chronic bronchitis, bronchiectasis, reactive airway disease, and carcinoma. In addition, vascular diseases of the respiratory tract can be life-threatening because of pulmonary embolism and pulmonary hypertension. Autoimmune diseases, vasculitis, and pneumoconiosis lead to fibrosis, scarring, and restriction. Various defining criteria are necessary for diagnosis and further definition of the impairment status of each of those diseases. Chronic lower respiratory diseases, especially COPD, constituted the third-leading cause of death in the United States in 2014. More than 6.4 percent of Americans reported having had a diagnosis of COPD, and the prevalence is higher in people over 65 years old. The prevalence of COPD varies considerably by state, from less than 4 percent in Colorado, Hawaii, and Utah to greater than 9 percent in Alabama, Kentucky, Tennessee, and West Virginia (CDC, 2017a). About 8 percent of working-age adults reported having asthma in 2015 (NCHS, 2017b).

The traditional means of establishing function of and diagnoses related to the respiratory tract involve chest x-ray and computed tomography/magnetic resonance imaging, pulmonary-function tests, diffusion capacity, bronchial-reactivity testing, cardiopulmonary exercise testing, and arterial blood gases. The AMA *Guides to the Evaluation of Permanent Impairment* states that ambulatory measurements, such as maximum postbronchodilator forced expiratory volume (FEV), are important for severity impairment ratings (AMA, 2008). Reactive airway challenge testing, such as methacholine challenge tests at below 0.50 PC(20) mg/mL, where PC—provocative concentration—(20) indicates a 20 percent fall in FEV, place patients or claimants who have asthma or other respiratory conditions at 25 percent impairment (Class 3 or 4) or worse with respect to the respiratory tract (AMA, 2008). As noted in the AMA *Guides* and SSA Listings, substantial reductions in activities of daily living (ADLs), inability to find gainful employment, terminal disease, multiple hospitalizations in a year, severe frequent exacerbations of oxygen supplementation, or ventilator assistance mark greater severity and possible disability. Respiratory disorders accounted for 2.6 percent of diagnoses of disability insurance beneficiaries in 2014 (SSA, 2015). "COPD and bronchiectasis" ranked in the top 10 conditions with the most all-causes, 30-day readmissions for Medicaid patients in 2011 with a readmissions rate of 25.2 per 100 admissions (AHRQ, 2014). They did not rank in the top 10 readmissions for privately insured patients in 2011.

Exacerbations of COPD requiring hospital admission have a major effect on progression of disease. COPD patients experience an average of one to two exacerbations per year. Patients who have more than three exacerbations per year demonstrate faster fall in FEV1 (forced expiratory volume in 1 second) (Celli et al., 2008) and greater airway inflammation when clinically stable (Bhowmik et al., 2000).

The committee found many reports of studies that examined health-care utilizations for COPD. A few associated health-care utilizations for COPD with disease severity by using such indicators as SpO_2 and BODE index score (Ekberg-Aronsson et al., 2008; Alcazar et al., 2012). Several studies show that COPD exacerbations that require hospitalizations predict severity of illness, but they do not indicate whether the hospitalizations predict ability to work (Fan et al., 2007; Mullerova et al., 2015). Using hospitalizations to predict severity of COPD seems to be a research subject of interest. In fact, Omachi et al. (2008) developed a dynamic prediction tool to use a COPD-severity score with sociodemographics, medical comorbidity, and tobacco history to

predict respiratory-specific health-care utilizations, including hospitalizations, ED visits, and outpatient visits. They found that adding a COPD-severity score to the basic model substantially increased the predictive value of the model. One study that looked at patients who had asthma found a relationship between hospitalizations for asthma exacerbation and lung-function decline (Bai et al., 2007).

CARDIOVASCULAR SYSTEM

Cardiovascular diseases (CVDs) accounted for 7.5 percent of diagnoses of disability insurance beneficiaries in 2014 (SSA, 2015).The most common impairing CVDs—excluding stroke—involve coronary heart disease, heart failure (HF), rhythm disorders, valvular disease, venous disease, and peripheral arterial disease (PAD) (Benjamin et al., 2017). The costs of CVDs to both the individual and the nation are great. More than one-third of US adults (92.1 million people) have CVDs (including hypertensive disease), which accounted for 807,775 deaths in 2014 (Benjamin et al., 2017). In 2015, about 6 percent of people who were 45–64 years old had self-reported coronary disease; about one-third reported having hypertensive disease (NCHS, 2017a). The 2017 Heart Disease and Stroke Statistics Update of the American Heart Association (Benjamin et al., 2017), which used national Medical Expenditure Panel Survey (MEPS) data, estimated the annual direct and indirect cost of CVDs in the United States as $316.1 billion (note, however, that the association's definition of CVD includes stroke).

The AMA *Guides* (AMA, 2008) define cardiovascular dysfunction on the basis of elements of cardiac function: history and physical examination findings, findings of objective tests of cardiac function, proven target-organ damage from CVDs, and proven established diagnoses. SSA Listings use established diagnoses, results of functional testing, hospitalizations, and arrhythmia assessments and treatment as criteria in disability determination.

Although the cardiovascular literature contains many studies of risk factors for specific diseases or factors related to improvements in care, there is little on utilizations that might serve as proxies for disability in working-age adults. The prevalence of CVDs increases with age, so the vast majority of studies involve people who are 65 years old or older, especially because of the availability of Medicare data on this population. In its review of the literature on the cardiovascular system, the committee concentrated on studies involving young or middle-aged adults in high-income countries. However, several studies involving older people were included if a factor deemed important for understanding utilization was found (e.g., Bibbins-Domingo et al., 2009; Bengtson et al., 2014; Mizutani et al., 2017). Of the studies involving adults under 65 years old, utilizations or functionality metrics were occasionally included, but none provided direct evidence for determining inability to return to work. Information that might provide guidance for addressing the SSA Listings, however, was not covered.

Studies that used a health-care utilization as a metric often evaluated trends in hospitalizations (Towfighi et al., 2011; Chamberlain et al., 2013; Badheka et al., 2015) or patient readmissions after a CVD event (Kim et al., 2009; Foraker et al., 2011; Yamada et al., 2012; Betihavas et al., 2015). All those studies, either directly via comparisons with people free of CVD or indirectly through other means, documented the higher rates of inpatient admissions associated with a specific cardiovascular condition. In some cases, the length of time between hospitalizations might be helpful in inferring the incapacity to work. Many epidemiologic investigations provided data to elucidate the factors inherent in subjects that predicted either utilization or functionality outcomes. The most striking finding in studies that used that approach

was the adverse effect of comorbidities on health (Fan et al., 2009; Foraker et al., 2011; Calvillo-King et al., 2013; Chamberlain et al., 2013; Agarwal et al., 2014; Badheka et al., 2015; Thorpe et al., 2016). Psychologic distress and depression were identified most consistently as predictors of disability or other functional outcomes. With respect to other comorbidities, people who had concomitant cardiovascular conditions (hypertension, diabetes, HF, arrhythmias, or PAD) or noncardiovascular diseases (asthma, COPD, arthritis, or renal disease) were also at higher risk for CVD progression. Many studies included demographic and social variables in their analyses. Most studies that included race as a covariate found that being nonwhite was a strong predictor of CVD outcomes (Bibbins-Domingo et al., 2009; Thomas et al., 2011; Calvillo-King et al., 2013; Thorpe et al., 2016), although not all studies agreed (Gambassi et al., 2008). Results on the effect of sex were mixed; studies generally reported no differences in adjusted models with the exception of myocardial infarction (Towfighi et al., 2011; Agarwal et al., 2014). The adverse influence of a multitude of socioeconomic factors has been documented. As in other body systems, many of the selected variables in CVD studies that examined socioeconomic status correlated, but studies generally found associations with such factors as low income, less education, unmarried status, rural residence, zip code or neighborhood value, home instability, and lack of social support (Foraker et al., 2011; Calvillo-King et al., 2013; Schofield et al., 2013; Agarwal et al., 2014).

Finally, although this review did not intend to focus on biomarkers as predictors of disease severity, the value of brain natriuretic peptide as a marker for CVD was identified (Allen et al., 2011; Mizutani et al., 2017). In conclusion, although the cardiovascular literature examined here was not exhaustive and this review was unable to provide utilizations as definitive markers by which SSA determinations of disability can be made, important factors to address during disability evaluations were revealed.

DIGESTIVE SYSTEM

Digestive diseases accounted for 1.5 percent of diagnoses of disability insurance beneficiaries in 2014 (SSA, 2015). Digestive system disorders include gastrointestinal (GI) hemorrhage, liver dysfunction, inflammatory bowel disease, short bowel syndrome, and malnutrition. They might lead to such complications as obstruction or have manifestations in other body systems. Digestive diseases are a leading cause of ambulatory care visits (Everhart and Ruhl, 2009), ED utilizations (Myer et al., 2013), and hospitalizations (Everhart and Ruhl, 2009). Everhart and Ruhl (2009) and Myer et al. (2013) demonstrated rising trends in GI-related hospitalizations and ED utilizations, respectively. However, despite the increase in ED visits, only 21 percent of those visits resulted in hospitalization (Myer et al., 2013). In addition to physician services, ED visits, and hospitalizations, health-care utilizations for digestive diseases include prescription drugs, diagnostic testing, nursing home care, and home health care (Everhart and Ruhl, 2009). In 2009, digestive diseases accounted for $85.2 billion in direct costs for personal health care measured by MEPS and the AHRQ (NHLBI, 2012).

Disease severity is determined primarily through laboratory findings and physical signs and symptoms, such as diarrhea, nausea and vomiting, and weight loss. The disorders often are treated with medication, therapy, and surgery.

Although the specific impact varies by digestive disease, factors associated with increased health-care utilization include the presence of psychologic comorbidities (Allegretti et

al., 2015), overlapping somatic complaints (Dudekula et al., 2011), symptom severity (Reilly et al., 2004; Wahlqvist et al., 2008), and response to disease-related therapy (Buono et al., 2014).

Factors associated with disability in digestive diseases have not been well studied except for inflammatory bowel disease. In Crohn's disease, disease-related characteristics—such as disease activity (Allen et al., 2013), fistulizing disease, duration of disease, number of relapses. and response to therapy—have been associated with loss of work productivity and disability (Siebert et al., 2013).

In some diseases, such as chronic pancreatitis (Mullady et al., 2011) and gastroparesis (Dudekula et al., 2011), pain frequency more than pain severity is associated with decreased quality of life (QOL), decreased work productivity, and increased health-care utilization. In patients who have chronic pancreatitis, the characteristic of pain (constant versus intermittent) but not severity of pain is associated with greater absenteeism, hospitalizations, and disability (Mullady et al., 2011). High illness-related absenteeism (defined as more than 15 absences/year) is associated with a greater risk of job termination, unemployability, or disability (Virtanen et al., 2006).

Overall, disease severity and presence of comorbidities are associated with greater impairment in QOL, health-care utilization, and disability. As with the other body systems, it is challenging to identify specific health-care utilizations that could serve as accurate proxies for disability. However, such disease-related characteristics as frequency, severity, and response to therapy are objectively quantifiable measures that have been associated with impairment in work productivity and QOL, which might serve as better proxies for disability. In addition to disease-specific characteristics, the presence of psychiatric disorders, sleep disturbance, and multiple somatic comorbidities is associated with a greater risk of disability in patients who have gastrointestinal diagnoses.

GENITOURINARY DISORDERS

Genitourinary diseases accounted for 1.6 percent of diagnoses of disability insurance beneficiaries in 2014. For the purposes of assessing disability, the three main categories of genitourinary disorders are chronic kidney disease (CKD), complications of CKD, and nephrotic syndrome. Genitourinary diseases account for $66.6 billion in direct costs for personal health care as measured by MEPS and AHRQ (NHLBI, 2012).

Two key health-care utilizations by which SSA determines the presence of severe CKD are dialysis and kidney transplantation. People who are undergoing dialysis are automatically classified as having Listing-level severity if dialysis has lasted or is expected to last for a continuous period of at least 12 months (SSA, 2017b). People who receive a kidney transplant are automatically classified as having Listing-level severity for 1 year after transplantation; the classification is revised later, depending on clinical status. Other measures of CKD used by SSA include reduced glomerular filtration (measured by serum creatinine, creatinine clearance, or estimated glomerular filtration rate) and the presence of comorbid conditions (renal osteodystrophy, peripheral neuropathy, fluid overload syndrome, or anorexia with weight loss). Tools used to identify CKD include laboratory, blood pressure, and anthropometric measurements and imaging studies. SSA uses laboratory findings to identify nephrotic syndrome, defined by proteinuria, serum albumin, urine protein:creatinine ratio, and anasarca (extreme generalized edema). To identify complications of CKD, SSA uses hospitalizations due

to stroke, congestive heart failure, hypertensive crisis, or acute kidney failure that requires a short course of hemodialysis.

There is some evidence that numbers of physician visits and hospitalizations can predict severity of CKD (Alexander et al., 2009). Although there is strong evidence in the literature that worsening of renal function is a predictor of mortality in acute decompensated heart failure (Damman et al., 2014; Ueda et al., 2014), fewer studies have examined this comorbidity as a predictor of longer-term outcomes.

HEMATOLOGIC DISORDERS

Hematologic diseases accounted for 0.3 percent of diagnoses of disability insurance beneficiaries in 2014 (SSA, 2015). Hematologic disorders include such nonmalignant conditions as hemolytic anemias (e.g., sickle-cell disease and the more specific sickle-cell anemia, a form of sickle-cell disease in which there are two sickle-cell genes), disorders of thrombosis and hemostasis, and disorders of bone-marrow failure (e.g., myelodysplastic syndromes, aplastic anemia, granulocytopenia, and myelofibrosis). Such malignant hematologic disorders as lymphoma, leukemia, and multiple myeloma are covered under other Listings. One exception is that disability resulting from bone marrow transplantation for any of the above conditions is covered under the hematologic disorders Listing. SSA uses health-care utilizations in addition to clinical measures to determine severity in this Listing. For instance, the Listing for hemolytic anemias includes a painful vaso-occlusive crisis requiring parenteral narcotic medication, occurring at least six times within a 12-month period at least 30 days apart *or* a complication that requires at least three hospitalizations within a 12-month period at least 30 days apart (each hospitalization lasting at least 48 hours) *or* hemoglobin measurements of 7 g/dL or less that occur at least three times within a 12-month period at least 30 days apart *or* beta-thalassemia major that requires life-long transfusions at least once every 6 weeks. Compared with diseases of other body systems, hematologic diseases are rare in the United States; for example, although the exact prevalence of sickle-cell anemia is unknown, the Centers for Disease Control and Prevention estimates that sickle-cell disease affects about 100,000 Americans (CDC, 2017b).

The AMA *Guides* (AMA, 2008) note that the severity of sickle-cell anemia depends on the cardiovascular system's compensatory response. AMA also notes that in persistent refractory anemia, the degree of impairment is related to the need for transfusion.

The committee found no literature relevant to determination of disability associated with other hematologic conditions on the basis of a health-service use. Hematologic Listings use hospitalizations as a criterion for receiving disability benefits. The literature suggests that not only frequent hospitalizations but also frequent ED visits are typical for sickle-cell patients (Brousseau et al., 2010). In addition, many factors other than the severity of the disease or disability resulting from the disease might predict hospital use and ED visits. They include the availability of good outpatient care (Leschke et al., 2012), distance from outpatient care (Wolfson et al., 2011), and insurance coverage (Wolfson et al., 2011). Changes in the health-care delivery system might render the three-hospital-stays-per-year criterion less valuable in the future inasmuch as hospital stays will undoubtedly decrease in length to less than 48 hours for crisis management. There might also be a shift to ED and urgent-care referral to outpatient care to manage a crisis.

SKIN DISORDERS

Skin diseases and burns accounted for 0.2 percent of diagnoses of disability insurance beneficiaries in 2014. Skin disorders might result from hereditary, congenital, or acquired pathologic processes. They include such impairments as ichthyosis, dermatitis, chronic infections of the skin or mucous membranes, and burns. The cost of skin disease in the United States 20 years ago was $35.9 billion, which included $7.2 billion in hospital inpatient charges (Dehkharghani et al., 2003). The indirect costs due to labor loss were estimated at $1.6 billion. Although skin disorders are seldom fatal, they can be terminal in some circumstances of burn, infection, cancer, inflammation, and severe allergic conditions.

Disease severity is generally determined according to the extent and frequency of flareups of skin lesions and the extent of treatment. The AMA *Guides* (AMA, 2008) call for evaluating impairment severity in skin conditions on the basis of the degree to which a condition persists after medical treatment and rehabilitation and affects ADLs.

The rate of hospitalization related to skin infection has increased over the past 20 years: hospitalization for skin infections has increased by 52 percent and for sepsis-related skin infections by 190 percent (Martin et al., 2003). Edelsberg et al. (2009) found in the 2000–2004 HCUP data that admissions for skin and soft-tissue infections increased by 29 percent over that 5-year period. Suaya and colleagues (2014) reported that hospitalization for soft-tissue infection due to community-associated methicillin-resistant *Staphylococcus aureus* increased by 122 percent (from 161,000 to 358,000) from 2001 to 2009 according to HCUP and Bureau of the Census.

In an analysis of data from the National Electronic Injury Surveillance System— Occupational Supplement for 1999–2008, Reichard et al. (2015) found that scalds and thermal burns made up greater than 60 percent of all burns. Most burns occurred in occupations related to accommodation and food service, manufacturing, and construction.

The committee found no evidence that particular utilizations are good indicators of impairment severity associated with skin diseases. The two studies summarized in Appendix C indicate that comorbid conditions are important determinants of health-care utilization for diseases related to this body system. There is evidence that obesity is a comorbid condition that impairs functional ability in burn patients (Farrell et al., 2008) and that psoriasis might increase risk of hospitalization of lymphoma patients (Kimball et al., 2014).

ENDOCRINE DISORDERS

Endocrine diseases accounted for 0.3 percent of diagnoses of disability insurance beneficiaries in 2014. Impairments of the endocrine system are caused by hormone overproduction or underproduction that results in structural or functional changes in the body. Examples are diabetes mellitus (DM), thyroid and parathyroid disorders, and pituitary disorders. In the United States, several endocrine disorders, such as DM and thyroiditis, have prevalences greater than 5 percent in adults (Golden et al., 2009). Changes in the body that indicate endocrine disorders can be determined through laboratory findings or imaging, such as x-ray imaging, computed axial tomography, and magnetic resonance imaging.

The committee found no evidence that links health-care utilization to severity of endocrine conditions, but it did find evidence that diabetes as a comorbid condition can affect the

frequency of health-care utilization by people who have cardiac disease (Jang et al., 2016; Nadjiri et al., 2016).

CONGENITAL DISORDERS THAT AFFECT MULTIPLE BODY SYSTEMS

The primary congenital disorder that affects multiple body systems is nonmosaic Down syndrome, which is diagnosed with a laboratory test. Down syndrome is generally diagnosed before or shortly after birth and only rarely in adulthood. There are about 6,000 diagnoses of Down syndrome in the United States each year (Parker et al., 2010). The syndrome is associated with distinctive physical characteristics, intellectual disability, higher risk of congenital heart defects, and higher incidences of infection, respiratory problems, vision and hearing impairments, and thyroid disorders. The committee's search on the use of health-care utilizations as indicators of impairment did not yield any articles related to congenital disorders that affect multiple body systems as defined by SSA.

NEUROLOGIC DISORDERS

Neurologic conditions accounted for 9.4 percent of diagnoses of disability insurance beneficiaries in 2014. Neurologic conditions encompass a wide array of disorders and injuries, and many people who have these conditions present with a continuum of impairment severity that can differentially affect their ability to work. Some examples of neurologic conditions are epilepsy, amyotrophic lateral sclerosis, parkinsonian syndrome, stroke, and brain injury. In 2011, nearly 100 million Americans had at least one neurologic disease. The number of years of life lost because of disability associated with neurologic and musculoskeletal disorders is greater than that associated with any other body system (Gooch et al., 2017). The prevalence of dementia, including Alzheimer dementia, is cited as 7.5 million, and the cost of dementia increases dramatically with increased severity because of the great need for daily care and assistance. The annual incidence of traumatic brain injury (TBI) in the United States is cited as 1.4–1.7 million. The risks of dementia and TBI increase with age (Gooch et al., 2017).

According to the AMA *Guides* (AMA, 2008), neurologic impairments should be assessed as they affect ADLs. Minimal impairment might be seen in a person who experiences epileptic seizures once every 2 months despite optimal medical intervention. Moderate impairment might be seen in a person who requires moderate assistance with ADLs, whereas severe impairment might be seen in a person who needs extensive assistive care throughout the day.

The relationship between health-care utilization for neurologic disorders and functional abilities, including ability to work, has received little study. Multiple sclerosis (MS) has probably been the most frequently studied neurologic disorder relevant to health-care utilization and disability. The committee found that people who had MS were more likely to use the hospital, ED, and rehabilitation therapy than those who did not have MS (Asche et al., 2010) and that patients who had more severe MS were more likely to be unemployed (Jones et al., 2016).

Overall, studies suggested that greater health-care utilization was associated with decreased likelihood of employment of people who had neurologic disorders. However, the direct relationship between health-care utilization and impairment severity or employment is rarely studied, and the types of health-care utilization most likely to be associated with SSA's definition of impairment severity have not been sufficiently evaluated.

MENTAL DISORDERS

Mental disorders accounted for 34 percent of diagnoses of disability insurance beneficiaries in 2014 (SSA, 2015). Mental disorders include schizophrenia, paranoia, psychotic disorders, autism and related disorders, personality disorders, substance addiction, depression, and intellectual disability. However, SSA does not consider a claimant to be disabled if drug addiction or alcoholism is a contributing factor material to the determination (SSA, 2017c). Mental disorders are among the most common diagnoses of disability insurance beneficiaries and are often seen in combination with disorders of other body systems. The disease burden of mental disorders is among the highest of all body systems. An estimated 18 percent of US adults suffer from any mental illness, including 4.2 percent who suffer from a seriously debilitating mental illness in any given year (HHS, 2014).

Two studies that examine mental disorders and their relationship to impairment severity are discussed in detail in Appendix C. One study of patients who had major depressive disorder found that utilization of prehospital resources predicted remission, whereas medication use was not associated with remission (Naz et al., 2007). A study of patients who had schizophrenia found that severity of illness predicted disability compensation (Rosenheck et al., 2017). The committee found many studies that focused on mental disorders as comorbidities. Specifically, they examined whether comorbid mental-health conditions affect health-care utilization, whether they affect disability, and whether they affect readmissions or duration of utilization. Those are summarized below. Finally, the committee gives an example of a prescription drug whose use could indicate impairment severity; this example is based on the committee's expert opinion, not on evidence found in the literature.

Comorbid Mental Disorders

In patients who had heart failure or other cardiac diseases, comorbid depression and anxiety were found to increase health-services utilization in a prospective study of 402 patients (Moraska et al., 2013). Bansil and colleagues (2009) found by using the 1994–2004 National Inpatient Sample that depression and anxiety were common reasons for hospitalization of women who had HIV and that the number of hospitalizations of such women for a diagnosis of psychiatric disorder increased from 1994 to 2004 while the overall number of hospitalizations of women who had HIV remained constant. An analysis of the 2012 National Emergency Department Sample concluded that HIV patients who had mental health and substance use disorders were more likely to be admitted to the hospital and ED than ones who did not (Choi et al., 2016). McMorris and colleagues (2010), in a cross-sectional survey of patients in seven states, found that comorbid bipolar I disorder was significantly associated with increased resource utilization (particularly office visits and ED visits) and with losses in work productivity.

In a longitudinal study of 1,632 subjects, comorbid anxiety and depression were found to lead to more work disability and absenteeism over 4 years (Hendriks et al., 2015). Another multisite longitudinal cohort study of 715 patients found that comorbid anxiety and depression led to increased risk of disability at 12 months after injury (O'Donnell et al., 2013). Both studies assessed disability at 12 months after injury by using the World Health Organization Disability Assessment Schedule 2.0.

In patients who had heart failure and other cardiac diseases, comorbid depression and anxiety were found to predict increased 30-day readmission in an analysis of the HMO Research

Network Virtual Data Warehouse (N = 160,169) (Ahmedani et al., 2015). In diabetes patients, comorbid serious mental illness was found in two studies to increase risk of 30-day readmission (Albrecht et al., 2012; Chwastiak et al., 2014). Comorbid serious mental illness was suggested to lead to increased risk of repeat hospitalization in general medical patients in a longitudinal cohort study of 925,705 adults in Washington state (Daratha et al., 2012).

Stephens and colleagues (2014) found in a case-control study of an urban trauma center that some mental health patients have extremely long stays. Factors that contribute to long stays include insurance status, admission to inpatient care, transfer to a remote facility, and suicidal ideation. The population consisted mostly of substance-abuse patients. Wolff and colleagues (2015) examined predictors of length of stay in psychiatry by looking at medical records at a psychiatric hospital and found that the most significant factors in predicting longer stays were affective disorders as a main diagnosis followed by disease severity and chronicity. Boaz et al. (2013) found that shorter inpatient stays led to greater readmission risk in patients who had serious mental illness. Tulloch (2011, 2012) found length of stay of patients who had mental-health disorders to be affected by several factors: length of stay was greater in larger medical centers, for homeless patients, and for psychotic patients and was lower for those who had insurance coverage limits, for those in areas that had fewer physicians per capita, and for those who had recent evidence of self-harm. Becerra et al. (2016) found that having any mental illness was associated with a 10 percent increase in length of hospital stay.

Douzenis et al. (2012) concluded in their analysis of factors that affect hospital stay of psychiatric patients that having a physical comorbidity as determined by referral to a medical subspecialty was a significant determinant. Depression led to poorer outcomes of colorectal surgery, including longer stay and requirement of skilled nursing assistance after discharge (Balentine et al., 2011). Zhang et al. (2011) noted that length of stay is multifactorially determined. It could be related to good clinical practice, social support, or location. Other factors that predict longer inpatient stays of people who have serious mental illness include stays in psychiatric hospitals, rather than general medical hospitals (Lee et al., 2012), and having Medicare or Medicaid (Lee et al., 2012; Masters et al., 2014).

Prescription Drug Use

If depression is comorbid with other health conditions, treatment for it could be a health-care utilization that indicates impairment severity associated with other health conditions. There are three domains of treatment for major depression: antidepressant medications, including medications approved for treatment-resistant depression; psychotherapy; and stimulation–convulsive therapies, such as electroconvulsive therapy. Evidence on sustained treatment of those kinds would support the presence of depression, which should then be considered as a contributory factor in overall impairment across conditions or evaluated as a stand-alone contributor to impairment. In any case, those utilizations do not provide a curative treatment for depression.

An example of use of a prescription drug as a potential indicator of severity is the use of clozapine. Clozapine is a treatment for schizophrenia that is reserved for two special circumstances: treatment resistance and persistent suicidal ideation or behavior. Treatment resistance is defined for the purposes of clozapine treatment as failure to respond, completely or nearly completely, to two standard courses of antipsychotic treatment. Thus, anyone who is receiving clozapine treatment has been determined to have evidence of functionally relevant

periods of extended decompensation, whose functional consequences have been judged to be extreme. Suicidal ideation or behavior has not been defined with the same level of precision.

Clozapine as a utilization entails various demands on the patient and the prescriber. Because of its potential side effects, clozapine requires biweekly blood monitoring, and prescriptions for it can be refilled only if there is evidence of compliance with the monitoring process. Although the actual time demands of the blood monitoring are not enough to preclude labor-force participation, the demands on clinicians tend to lead to clozapine being prescribed only in specialty clinics wherein regular attendance is required and medication is dispensed in person every 2 weeks.

Empirical evidence suggests that only about one-third of patients who are treated with clozapine experience successful treatment (Lieberman et al., 1994; McEnvoy et al., 2006; Friedman et al., 2011). Even in patients who achieve clinical stability, clozapine treatment does not directly improve functional disability. It should be noted that absence of clozapine use is not evidence of lower severity.

In summary, for mental health disorders, the committee's literature review found no evidence that health-care utilizations are a good indicator of impairment severity for the purposes of the disability program. The majority of the literature that the committee reviewed concluded that comorbid mental disorders can indicate disease severity in people who present with other diseases. That could be because people who have comorbid mental disorders are especially vulnerable to the consequences of disease and might have more difficulty in accessing health-care services. That is particularly true for depression as a mental disorder and for a cardiac condition as the physical condition. Length of stay tends to be greater overall for mental disorders than for disorders of other body systems (AHRQ, 2017a), and that is influenced by many factors, including behavioral manifestations of illness, lack of social support, quality of clinical care, and changing structures of payment systems. Downey and Zun (2015) suggested that in all the comorbid mental health conditions, a two-pronged approach to treatment, focusing on both mental illness and physical illness, might be developed to reduce readmission rates in this population.

Although the committee found no evidence in the literature to suggest health-care utilizations as indicators of severity, psychiatry experts on the committee suggested that use of the prescription drug clozapine might be an indicator of severity. Clozapine is a unique medication used to treat a subset of the schizophrenia population, that is, those who have already demonstrated consistent failures to respond to other treatments. In contrast with other treatments that are used for mental illness in general, the prescription of clozapine provides information about treatment and functional history. Furthermore, because it is regulated and cannot be dispensed without agreement on the part of clinicians and patients to have treatment monitored, the decision to prescribe it comes with more planning and consideration than are required for any similar treatment.

CANCER

Neoplastic diseases (cancers) accounted for 2.8 percent of diagnoses of disability insurance beneficiaries in 2014. Health-care utilization related to a cancer diagnosis can depend heavily on the site of the cancer, the stage at diagnosis, and the treatment provided. The cancer itself, depending on symptoms through progression of the disease, can cause substantial morbidity that might have important implications for the ability to work. Depending on site and

stage, various treatment options might be offered to patients that provide, if not a cure, a remission. However, treatment in the form of surgery, radiation therapy, chemotherapy, and other procedures might also result in adverse effects that elicit new symptoms that affect functionality. More than 1.5 million people receive a diagnosis of cancer each year in the United States, and the number of new cases is expected to increase to 2 million per year in 2020 (CDC, 2016).

Cancer severity is often described in stages that reflect tumor size, location, growth, and spread. Cancers originating in different organ systems and with different cell types differ in prognosis and course of treatment. Some cancer types have very short life expectancies; most people who receive a diagnosis of lung or pancreatic cancer die well before they can qualify for Social Security disability insurance.

The literature provides minimal insights into the relationship between specific types of cancers and disability. Although it has been acknowledged that the "long-term effects of cancer and its treatment on employment and productivity are a major concern for the 40 percent of cancer survivors in the US who are of working age" (Short et al., 2008), there have been relatively few attempts to measure the increase in disability attributable to cancer in the years after initial treatment (Bradley, 2002; Chirikos, 2002; Hewitt, 2003; Yabroff, 2004; Short et al., 2005). The prevalence of disability in cancer survivors cannot be denied.

Overall, the articles identified in the committee's literature review, although not comprehensive, revealed the effects of increased disability and reduced functionality on cancer survivors; trends in modern screening and diagnosis might allow more working-age adults to return to employment after a diagnosis of cancer. There is a paucity of studies that documented utilization related to disabilities. In addition to the variability inherent in different cancers and effects of treatment, there is evidence that race, socioeconomic status, and access to care in connection with different forms of cancer can be different (Parsons et al., 2012; Simpson et al., 2013). Data on hospitalization frequency and duration associated with advanced tumors and cancers vary considerably by type and stage of cancer. Any relationship between utilization and severity is contingent on the stage of disease at the time of diagnosis. There is little in the literature to permit generalizations on health-care utilization that can predict disability in adult cancer survivors who are under 65 years old.

IMMUNE-SYSTEM DISORDERS

Immune-system disorders include immune-deficiency disorders, such as HIV, and autoimmune disorders, such as systemic lupus erythematosus (SLE). Immune-deficiency disorders are characterized by congenital or acquired recurrent infections that respond poorly to treatment. Autoimmune disorders are caused by dysfunctional immune responses directed against the body's own tissues. It is estimated that in 2014 there were 37,600 new cases of HIV in the United States. The annual number of new cases has declined by 10 percent since 2010. In 2014, 62 percent of people who were living with HIV received medical treatment; 48 percent of them received continuous HIV care (CDC, 2017c). The extent of HIV infection can be characterized by CD4 count.

The committee found several studies that suggested an association between utilization and disease severity in people who had HIV/AIDS or SLE. The studies suggest that frequency of ED visits might reflect disease severity in patients who have SLE (Panopalis et al., 2010) and HIV (Josephs et al., 2010), that greater clinical severity is associated with increased hospital

utilization by HIV and AIDS patients (Yehia et al., 2010; Kerr et al., 2012), that hospital readmission could be associated with disease severity in SLE patients (Yazdany et al., 2014), and that frequency of outpatient-clinic use might reflect disease severity in HIV patients (Palma et al., 2015). Details of these studies can be found in Appendix C. It should be noted that the studies were designed to evaluate clinical measures of severity, such as CD4 count, SLAQ scores, and the Ward Index rather than SSA's definition of disability.

HOW HEALTH-CARE UTILIZATIONS INTERFERE WITH THE ABILITY TO WORK

As severity of disease increases or as the number of conditions increases, overall health declines and utilization increases (NCHS, 2017a). Therefore, increased utilization is, on average, associated with less ability to work because people are sicker or more impaired. However, utilization is only indirectly related to ability to work, and the periods between utilization and work or work disability vary with the specific disease and with conditions of employment. Utilization is directly related to a specific diagnosis or condition, not to a person's ability to function overall. Each disease or condition has its trajectory, which interacts with the patient's characteristics. Ability to work is a continuing state, whereas utilization takes place at a particular point in time. Ability to work is a function of numerous factors. Health is also a function of a number of factors, of which health-care utilization is only one, as discussed in Chapter 2.

Workplaces are becoming more accommodating for people who receive health care, but people undergoing, for example, chemotherapy or radiation therapy, dialysis, or supplemental oxygen therapy might have difficulty in maintaining a work schedule. The act of managing one's health—including the utilization of health care—can itself interfere with one's ability to work. Walter Oi (1992) noted that disability "steals time" from people by increasing the demands for personal care or rehabilitative services. In the case of health care specifically, the frequency of use (e.g., if a person is hospitalized every few weeks or months or requires weekly dialysis) has traditionally been recognized as a barrier to employment. That would be particularly true for acute hospitalizations, which can occur unexpectedly during the work week and in the workplace. However, it is also important to acknowledge that other factors—such as the duration of utilization (e.g., length of hospital stay), the time spent in receiving treatment, or the side effects of treatment (e.g., for many types of cancer)—can affect one's ability to work.

Even if a person does not require hospital confinement, a health condition might require treatment that precludes employment or at least hampers the ability to be employed. The committee reviewed recent papers that examined the ability to work while undergoing chemotherapy, dialysis, and supplemental oxygen therapy.

A study by Mujahid et al. (2010) examined results of a survey of women who had nonmetastatic breast cancer and noted that many women stop work altogether after a diagnosis of breast cancer, particularly if they belong to racial or ethnic minorities, receive chemotherapy, or are in an unsupportive work setting. Women who received a mastectomy and those receiving chemotherapy were more likely to stop working independently of sociodemographic and treatment factors.

Patients who were undergoing final cycles of adjuvant chemotherapy for breast or colorectal cancer or first-line chemotherapy for lymphoma in two cancer treatment centers were approached to take part in a cross-sectional survey. Some 64 percent of respondents were

working when cancer was diagnosed; 54 percent were working when chemotherapy began; and only 29 percent continued to work in any capacity as treatment progressed.

Another study, by Jagsi et al. (2014), demonstrated that unemployment is common among breast-cancer survivors 4 years after diagnosis and appears to be related to the receipt of chemotherapy during initial treatment. The authors conducted a longitudinal multicenter cohort study of women who had diagnoses of nonmetastatic breast cancer in 2005–2007, as reported to Los Angeles and Detroit Surveillance, Epidemiology, and End Results program registries.[3] Some 76 percent (746) of the women worked for pay before diagnosis; 68 percent (507) of those were working 4 years later.

Munir et al. (2009) reviewed 19 studies published in 1999–2008 on cancer and ability to work. The authors noted that people undergoing treatment for cancer are likely to have poorer ability to work than healthy people and those who have such chronic conditions as depression, heart disease, and diabetes. They also noted that type of treatment, particularly chemotherapy, has a substantial effect on ability to work.

A study of the differences between employed and nonemployed dialysis patients found that education correlated significantly with employment. The authors (Curtin et al., 1996) noted that neither mode of dialysis, length of time on dialysis, number of comorbid conditions, nor cause of renal failure was associated with employment status. Functional status was positively associated with employment. The authors also noted that patients who believed that dialysis patients should work and had that notion reinforced by significant others were more likely to be employed.

Muehrer et al. (2011) conducted a study to understand factors associated with maintaining employment among working-age patients who had advanced kidney failure. The authors conducted a retrospective review of the US Renal Data System database (1992–2003) and selected all patients (N = 102,104) who were of working age and employed 6 months before dialysis initiation. Large numbers of patients stopped working or reduced their work hours before or after initiating dialysis. However, the authors maintained that loss of employment is not inevitable, and some patients continued to work as their kidneys failed. The authors posited that one factor in discontinuing work might be anemia, which if untreated could lead to fatigue and adversely affect a person's ability to work. Another possible factor is the dialysis modality. For example, hemodialysis in a center usually requires three sessions per week for 3–4 hours, but peritoneal dialysis provides patients with more options for treatment. Finally, the type of health insurance that a patient has can influence whether employment continues; patients covered by employer group-health plans might be motivated to keep working.

The committee reviewed several studies that were related to the need for supplemental oxygen therapy for COPD. Owing to its progressive and debilitating nature, COPD has the potential to interfere with a person's ability to work. Adhering to oxygen therapy can be complex and difficult for some, including the physical difficulty of using oxygen, self-consciousness, and a sense of social stigma (Earnest, 2002). Other studies have revealed an association between COPD hospitalizations and work loss (e.g., Sin et al., 2002; Fletcher et al., 2011; Dhamane et al., 2016).

The committee notes that health-care utilizations, particularly frequent and time-intensive utilizations, interfere with a person's ability to work. In addition, the length of time and the

---

[3]The Surveillance, Epidemiology, and End Results program of the National Cancer Institute provides information on cancer statistics.

number of treatments, the severity of side effects, self-consciousness, and social stigma compound a person's ability to work.

The committee's extensive literature review found no studies that addressed the usefulness of health-care utilizations in determining disability or impairment severity and few that addressed the association of health-care utilization with disability. The question of whether health-care utilizations can be proxies for disability or impairment severity according to SSA's definition has not been extensively researched in the health sciences. In the absence of such data, the committee reviewed literature that links health-care utilizations to similar concepts, such as disease severity and ability to work. The committee's review led it to draw several conclusions.

The committee found no evidence that health-care utilizations alone can predict disability, impairment severity, or disease severity. For several medical conditions, including COPD and CKD, there is some evidence that increased hospitalizations, ED visits, and outpatient physician visits might predict disease severity for some specific diagnoses. However, their relevance to the committee's task is limited in that disease severity does not fit SSA's definition of impairment severity and statistical modeling in the supporting papers involved more factors than health-care utilization. The other factors could be social factors, insurance, hospital factors, geographic factors, and personal factors. Those factors, many of which are discussed in Chapter 2, limit the classifying power of health-care utilizations in determining disability and impairment severity.

Another intervening factor that complicates the picture is the presence of comorbid conditions. Many of the studies that the committee reviewed discussed the influence of comorbidities in predicting health-care utilizations and health outcomes. In particular, psychiatric disorders were found to increase the likelihood of disability associated with and use of health-care services to address medical conditions of several body systems. Most of the literature found on mental disorders was related to their use as comorbid conditions that can predict increased resource utilization by, greater disability of, and greater length of hospital stay of patients who have various health conditions.

SUMMARY AND CONCLUSIONS

With few exceptions the health-care utilizations featured in the committee's literature review were hospitalizations, ED visits, and outpatient physician visits. Given that annual data on hospitalizations have been collected in the United States since 1965, hospital data are easy to capture and are more likely than data on other utilizations to constitute a reliable measure of impairment severity associated with some diseases. However, care is given in many other settings, such as dialysis centers, urgent care centers, and ambulatory care centers, and health-care laws encourage the use of health-care delivery sites other than hospitals. This fragmented health-care delivery system makes it difficult to capture all the different types and locations of utilizations for purposes of determining disease severity.

The committee's review of HCUP data corroborated its literature findings that numbers and rates of hospitalizations and ED visits alone do not indicate severity of a condition; they only suggest that a hospitalization or ED visit appeared necessary. Event-level data tell little about the continuing severity of a condition. The committee did not find the data useful in determining how types of utilizations are more or less probable for particular medical conditions, but it found that utilization is more related to sets of conditions, and analysis of which specific conditions should be grouped is extremely complex and faces many data limitations. The committee

suggests that specific diagnoses are more predictive of patterns of utilization than vice versa. The HCUP data could provide insight into which health conditions prevent a person from working, if only because the act of using a health-care service prevents a person from being at work. However, they are not informative with respect to whether these utilizations are useful for indicating disease severity or inability to work.

Little research has attempted to account for the relationships among employment, health, and disability. Some studies explore effects of health on disability or vice versa but rarely in a manner that acknowledges that health interferes with the ability to work. Different types of employment are more or less supportive of particular health conditions because of the availability of sick leave or other working conditions. For example, white-collar places of employment might be more supportive of musculoskeletal conditions than places of employment where physical labor is required. In addition, most studies rely on data collected over short timeframes and have little or delayed followup because of the cost of continuing data collection and of following up with respondents.

The committee concludes that types of health-care utilizations vary with combinations of health conditions. Although there might be a connection between some utilizations and impairment severity or disability, the committee could not make that specific connection on the basis of available data. It was not possible for the committee to link disability (the restriction of the ability to perform "substantial gainful activity") in the context of its statement of task universally to a single health-care utilization. Linking health-care utilizations to impairment severity and disability is complex. Although datasets on utilization and function exist, it is not possible to associate a specific type of utilization with a specific condition without longitudinal data on all types of utilization, multiple specific diagnoses, and multiple levels of function.

REFERENCES

Agarwal, S., A. Garg, A. Parashar, W. A. Jaber, and V. Menon. 2014. Outcomes and resource utilization in ST-elevation myocardial infarction in the United States: Evidence for socioeconomic disparities. *Journal of the American Heart Association* 3(6):e001057.

Ahmedani, B. K., L. I. Solberg, L. A. Copeland, Y. Fang-Hollingsworth, C. Stewart, J. Hu, D. R. Nerenz, L. K. Williams, A. E. Cassidy-Bushrow, J. Waxmonsky, C. Y. Lu, B. E. Waitzfelder, A. A. Owen-Smith, K. J. Coleman, F. L. Lynch, A. T. Ahmed, A. Beck, R. C. Rossom, and G. E. Simon. 2015. Psychiatric comorbidity and 30-day readmissions after hospitalization for heart failure, AMI, and pneumonia. *Psychiatric Services* 66(2):134–140.

AHRQ (Agency for Healthcare Research and Quality). 2014. *HCUP statistical brief #172: Conditions with the largest number of adult hospital readmissions by payer, 2011*. Bethesda, MD: AHRQ. https://www.hcup-us.ahrq.gov/reports/statbriefs/sb172-Conditions-Readmissions-Payer.pdf (accessed February 5, 2018).

AHRQ. 2017a. *HCUPnet, healthcare cost and utilization project*. https://hcupnet.ahrq.gov/#setup (accessed May 27, 2017).

AHRQ. 2017b. *HCUP frequently asked questions*. https://www.hcup-us.ahrq.gov/tech_assist/faq.jsp (accessed May 27, 2017).

Albrecht, J. S., J. M. Hirshon, R. Goldberg, P. Langenberg, H. R. Day, D. J. Morgan, A. C. Comer, A. D. Harris, and J. P. Furuno. 2012. Serious mental illness and acute hospital readmission in diabetic patients. *American Journal of Medical Quality* 27(6):503–508.

Alcazar, B., C. Garcia-Polo, A. Herrejon, L. A. Ruiz, J. de Miguel, J. A. Ros, P. Garcia-Sidro, G. T. Conde, J. L. Lopez-Campos, C. Martinez, J. Costan, M. Bonnin, S. Mayoralas, and M. Miravitlles. 2012. Factors associated with hospital admission for exacerbation of chronic obstructive pulmonary disease. *Archivos de Bronconeumologia* 48(3):70–76.

Alexander, M., B. D. Bradbury, R. Kewalramani, A. Barlev, S. A. Mohanty, and D. Globe. 2009. Chronic kidney disease and US healthcare resource utilization in a nationally representative sample. *American Journal of Nephrology* 29(5):473–482.

Allegretti, J. R., L. Borges, M. Lucci, M. Chang, B. Cao, E. Collins, B. Vogel, E. Arthur, D. Emmons, and J. R. Korzenik. 2015. Risk factors for rehospitalization within 90 days in patients with inflammatory bowel disease. *Inflammatory Bowel Diseases* 21(11):2583–2589.

Allen, L. A., M. Gheorghiade, K. J. Reid, S. M. Dunlay, P. S. Chan, P. J. Hauptman, F. Zannad, M. A. Konstam, and J. A. Spertus. 2011. Identifying patients hospitalized with heart failure at risk for unfavorable future quality of life. *Circulation: Cardiovascular Quality and Outcomes* 4(4):389–398.

Allen, P. B., M. A. Kamm, L. Peyrin-Biroulet, C. Studd, C. McDowell, B. C. Allen, W. R. Connell, P. P. De Cruz, S. J. Bell, R. P. Elliot, S. Brown, P. V. Desmond, M. Lemann, and J. F. Colombel. 2013. Development and validation of a patient-reported disability measurement tool for patients with inflammatory bowel disease. *Alimentary Pharmacology & Therapeutics* 37(4):438–444.

AMA (American Medical Association). 2008. *AMA guides to the evaluation of permanent impairment, sixth edition.* Chicago, IL: American Medical Association.

Asche, C. V., M. E. Singer, M. Jhaveri, H. Chung, and A. Miller. 2010. All-cause health care utilization and costs associated with newly diagnosed multiple sclerosis in the United States. *Journal of Managed Care & Specialty Pharmacy* 16(9):703–712.

Badheka, A. O., V. Singh, N. J. Patel, S. Arora, N. Patel, B. Thakkar, S. Jhamnani, S. Pant, A. Chothani, C. Macon, S. S. Panaich, J. Patel, S. Manvar, C. Savani, P. Bhatt, V. Panchal, N. Patel, A. Patel, D. Patel, S. Lahewala, A. Deshmukh, T. Mohamad, A. A. Mangi, M. Cleman, and J. K. Forrest. 2015. Trends of hospitalizations in the United States from 2000 to 2012 of patients >60 years with aortic valve disease. *American Journal of Cardiology* 116(1):132–141.

Bai, T. R., J. M. Vonk, D. S. Postma, and H. M. Boezen. 2007. Severe exacerbations predict excess lung function decline in asthma. *The European Respiratory Journal* 30(3):452–456.

Balentine, C. J., J. Hermosillo-Rodriguez, C. N. Robinson, D. H. Berger, and A. D. Naik. 2011. Depression is associated with prolonged and complicated recovery following colorectal surgery. *Journal of Gastrointestinal Surgery* 15(10):1712–1717.

Bansil, P., D. J. Jamieson, S. F. Posner, and A. P. Kourtis. 2009. Trends in hospitalizations with psychiatric diagnoses among HIV-infected women in the USA, 1994-2004. *AIDS Care* 21(11):1432–1438.

Becerra, B. J., J. E. Banta, M. Ghamsary, L. R. Martin, and N. Safdar. 2016. Burden of mental illness on hospital and patient outcomes among asthma hospitalizations. *Journal of Asthma* 53(4):392–397.

Bengtson, L. G., P. L. Lutsey, L. R. Loehr, A. Kucharska-Newton, L. Y. Chen, A. M. Chamberlain, L. M. Wruck, S. Duval, S. C. Stearns, and A. Alonso. 2014. Impact of atrial fibrillation on healthcare utilization in the community: The atherosclerosis risk in communities study. *Journal of the American Heart Association* 3(6):e001006.

Benjamin, E. J., M. J. Blaha, S. E. Chiuve, M. Cushman, S. R. Das, R. Deo, S. D. de Ferranti, J. Floyd, M. Fornage, C. Gillespie, C. R. Isasi, M. C. Jiménez, L. C. Jordan, S. E. Judd, D. Lackland, J. H. Lichtman, L. Lisabeth, S. Liu, C. T. Longenecker, R. H. Mackey, K. Matsushita, D. Mozaffarian, M. E. Mussolino, K. Nasir, R. W. Neumar, L. Palaniappan, D. K. Pandey, R. R. Thiagarajan, M. J. Reeves, M. Ritchey, C. J. Rodriguez, G. A. Roth, W. D. Rosamond, C. Sasson, A. Towfighi, C. W. Tsao, M. B. Turner, S. S. Virani, J. H. Voeks, J. Z. Willey, J. T. Wilkins, J. H. Y. Wu, H. M. Alger, S. S. Wong, and P. Muntner. 2017. Heart disease and stroke statistics—2017 update: A report from the American Heart Association. *Circulation* 135(10):e146–e603.

Betihavas, V., S. A. Frost, P. J. Newton, P. Macdonald, S. Stewart, M. J. Carrington, Y. K. Chan, and P. M. Davidson. 2015. An absolute risk prediction model to determine unplanned cardiovascular readmissions for adults with chronic heart failure. *Heart, Lung and Circulation* 24(11):1068–1073.

Bhowmik, A., T. A. Seemungal, R. J. Sapsford, and J. A. Wedzicha. 2000. Relation of sputum inflammatory markers to symptoms and lung function changes in COPD exacerbations. *Thorax* 55(2):114–120.

Bibbins-Domingo, K., M. J. Pletcher, F. Lin, E. Vittinghoff, J. M. Gardin, A. Arynchyn, C. E. Lewis, O. D. Williams, and S. B. Hulley. 2009. Racial differences in incident heart failure among young adults. *The New England Journal of Medicine* 360(12):1179–1190.

Boaz, T. L., M. A. Becker, R. Andel, R. A. Van Dorn, J. Choi, and M. Sikirica. 2013. Risk factors for early readmission to acute care for persons with schizophrenia taking antipsychotic medications. *Psychiatric Services* 64(12):1225–1229.

Bradley, C. J., and H. L. Bednarek. 2002. Employment patterns of long-term cancer survivors. *Psychooncology* 11(3):188–198.

Brousseau, D. C., P. L. Owens, A. L. Mosso, J. A. Panepinto, and C. A. Steiner. 2010. Acute care utilization and rehospitalizations for sickle cell disease. *JAMA* 303(13):1288–1294.

Buono, J. L., S. Tourkodimitris, P. Sarocco, J. M. Johnston, and R. T. Carson. 2014. Impact of linaclotide treatment on work productivity and activity impairment in adults with irritable bowel syndrome with constipation: Results from 2 randomized, double-blind, placebo-controlled phase 3 trials. *American Health & Drug Benefits* 7(5):289–297.

Calvillo-King, L., D. Arnold, K. J. Eubank, M. Lo, P. Yunyongying, H. Stieglitz, and E. A. Halm. 2013. Impact of social factors on risk of readmission or mortality in pneumonia and heart failure: Systematic review. *Journal of General Internal Medicine* 28(2):269–282.

CDC (Centers for Disease Control and Prevention). 2016. *Cancer: Preventing one of the nation's leading causes of death at a glance 2016.* Atlanta, GA: CDC. https://www.cdc.gov/chronicdisease/resources/publications/aag/dcpc.htm (accessed October 31, 2017).

CDC. 2017a. *Chronic obstructive pulmonary disease (COPD).* Atlanta, GA: CDC. https://www.cdc.gov/copd/index.html (accessed October 31, 2017).

CDC. 2017b. *Sickle cell disease (SCD).* Atlanta, GA: CDC. https://www.cdc.gov/ncbddd/sicklecell/data.html (accessed October 31, 2017).

CDC. 2017c. *HIV in the United States: At a glance.* Atlanta, GA: CDC. https://www.cdc.gov/hiv/statistics/overview/ataglance.html (accessed October 31, 2017).

Celli, B. R., N. E. Thomas, J. A. Anderson, G. T. Ferguson, C. R. Jenkins, P. W. Jones, J. Vestbo, K. Knobil, J. C. Yates, and P. M. Calverley. 2008. Effect of pharmacotherapy on rate of decline of lung function in chronic obstructive pulmonary disease: Results from the Torch Study. *American Journal of Respiratory and Critical Care Medicine* 178(4):332–338.

Chamberlain, A. M., S. J. Bielinski, S. A. Weston, W. Klaskala, R. M. Mills, B. J. Gersh, A. Alonso, and V. L. Roger. 2013. Atrial fibrillation in myocardial infarction patients: Impact on health care utilization. *American Heart Journal* 166(4):753–759.

Chirikos, T. N., A. Russell-Jacobs, and P. B. Jacobsen. 2002. Functional impairment and the economic consequences of female breast cancer. *Women's Health* 36(1):1–20.

Choi, B. Y., D. M. DiNitto, C. N. Marti, and N. G. Choi. 2016. Impact of mental health and substance use disorders on emergency department visit outcomes for HIV patients. *The Western Journal of Emergency Medicine* 17(2):153–164.

Chwastiak, L. A., D. S. Davydow, C. L. McKibbin, E. Schur, M. Burley, M. G. McDonell, J. Roll, and K. B. Daratha. 2014. The effect of serious mental illness on the risk of rehospitalization among patients with diabetes. *Psychosomatics* 55(2):134–143.

Curtin, R. B., E. T. Oberley, P. Sacksteder, and A. Friedman. 1996. Differences between employed and nonemployed dialysis patients. *American Journal of Kidney Disease* 27(4):533–540.

Damman, K., M. A. E. Valente, A. A. Voors, C. M. O'Connor, D. J. van Veldhuisen, and H. L. Hillege. 2014. Renal impairment, worsening renal function, and outcome in patients with heart failure: An updated meta-analysis. *European Heart Journal* 35(7):455–469.

Daratha, K. B., C. Barbosa-Leiker, M. H. Burley, R. Short, M. E. Layton, S. McPherson, D. G. Dyck, B. H. McFarland, and K. R. Tuttle. 2012. Co-occurring mood disorders among hospitalized patients and risk for subsequent medical hospitalization. *General Hospital Psychiatry* 34(5):500–505.

Dehkharghani, S., J. Bible, J. G. Chen, S. R. Feldman, and A. B. Fleischer, Jr. 2003. The economic burden of skin disease in the United States. *Journal of the American Academy of Dermatology* 48(4):592–599.

Dhamane, A. D., E. A. Witt, and J. Su. 2016. Associations between COPD severity and work productivity, health-related quality of life, and health care resource use: A cross-sectional analysis of national survey data. *Journal of Occupational and Environmental Medicine* 58(6):e191–e197.

Douzenis, A., D. Seretis, S. Nika, P. Nikolaidou, A. Papadopoulou, E. N. Rizos, C. Christodoulou, C. Tsopelas, D. Mitchell, and L. Lykouras. 2012. Factors affecting hospital stay in psychiatric patients: The role of active comorbidity. *BMC Health Services Research* 12:166.

Downey, L. V., and L. S. Zun. 2015. Reasons for readmissions: What are the reasons for 90-day readmissions of psychiatric patients from the ED? *American Journal of Emergency Medicine* 33(10):1489–1491.

Dudekula, A., M. O'Connell, and K. Bielefeldt. 2011. Hospitalizations and testing in gastroparesis. *Journal of Gastroenterology and Hepatology* 26(8):1275–1282.

Earnest, M. A. 2002. Explaining adherence to supplemental oxygen therapy: The patient's perspective. *Journal of General Internal Medicine* 17(10):749–755.

Edelsberg, J., C. Taneja, M. Zervos, N. Haque, C. Moore, K. Reyes, J. Spalding, J. Jiang, and G. Oster. 2009. Trends in US hospital admissions for skin and soft tissue infections. *Emerging Infectious Diseases Journal* 15(9):1516–1518.

Ekberg-Aronsson, M., K. Lofdahl, J. A. Nilsson, C. G. Lofdahl, and P. M. Nilsson. 2008. Hospital admission rates among men and women with symptoms of chronic bronchitis and airflow limitation corresponding to the gold stages of chronic obstructive pulmonary disease—a population-based study. *Respiratory Medicine* 102(1):109–120.

Everhart, J. E., and C. E. Ruhl. 2009. Burden of digestive diseases in the United States part iii: Liver, biliary tract, and pancreas. *Gastroenterology* 136(4):1134–1144.

Fan, A. Z., T. W. Strine, R. Jiles, J. T. Berry, and A. H. Mokdad. 2009. Psychological distress, use of rehabilitation services, and disability status among noninstitutionalized US adults aged 35 years and older, who have cardiovascular conditions, 2007. *International Journal of Public Health* 54(Suppl 1):100–105.

Fan, V. S., S. D. Ramsey, B. J. Make, and F. J. Martinez. 2007. Physiologic variables and functional status independently predict COPD hospitalizations and emergency department visits in patients with severe COPD. *Journal of Chronic Obstructive Pulmonary Disease* 4(1):29–39.

Farrell, R. T., R. L. Gamelli, R. F. Aleem, and J. M. Sinacore. 2008. The relationship of body mass index and functional outcomes in patients with acute burns. *Journal of Burn Care & Research* 29(1):102–108.

Finlayson, T. L., C. A. Moyer, and S. S. Sonnad. 2004. Assessing symptoms, disease severity, and quality of life in the clinical context: A theoretical framework. *American Journal of Managed Care* 10(5):336–344.

Fletcher, M. J., J. Upton, J. Taylor-Fishwick, S. A. Buist, C. Jenkins, J. Hutton, N. Barnes, T. Van Der Molen, J. W. Walsh, P. Jones, and S. Walker. 2011. COPD uncovered: An international survey on the impact of chronic obstructive pulmonary disease [COPD] on a working age population. *BMC Public Health* 11:612.

Foraker, R. E., K. M. Rose, C. M. Suchindran, P. P. Chang, A. M. McNeill, and W. D. Rosamond. 2011. Socioeconomic status, Medicaid coverage, clinical comorbidity, and rehospitalization or death after an incident heart failure hospitalization: Atherosclerosis risk in communities cohort (1987 to 2004). *Circulation: Heart Failure* 4(3):308–316.

Friedman, J. I., J.-P. Lindenmayer, F. Alcantara, S. Bowler, M. Parak, L. White, A. Iskander, M. Parrella, D. N. Adler, N. D. Tsopelas, W.-Y. Tsai, V. Novakovick, P. D. Harvey, and K. L. Davis. 2011. Pimozide augmentation of clozapine inpatients with schizophrenia and schizoaffective disorder unresponsive to clozapine monotherapy. *Neuropsychopharmacology* 36(6):1289–1295.

Gambassi, G., S. A. Agha, X. Sui, C. W. Yancy, J. Butler, G. Giamouzis, T. E. Love, and A. Ahmed. 2008. Race and the natural history of chronic heart failure: A propensity-matched study. *Journal of Cardiac Failure* 14(5):373–378.

Golden, S. H., K. A. Robinson, I. Saldanha, B. Anton, and P. W. Ladenson. 2009. Prevalence and incidence of endocrine and metabolic disorders in the United States: A comprehensive review. *The Journal of Clinical Endocrinology and Metabolism* 94(6):1853–1878.

Gooch, C. L., E. Pracht, and A. R. Borenstein. 2017. The burden of neurological disease in the United States: A summary report and call to action. *Annals of Neurology* 81(4):479–484.

Hendriks, S. M., J. Spijker, C. M. Licht, F. Hardeveld, R. de Graaf, N. M. Batelaan, B. W. Penninx, and A. T. Beekman. 2015. Long-term work disability and absenteeism in anxiety and depressive disorders. *Journal of Affective Disorders* 178:121–130.

Hewitt, M., J. H. Rowland, and R. Yancik. 2003. Cancer survivors in the United States: Age, health, and disability. *The Journals of Gerontology. Series A, Biological Sciences and Medical Sciences* 58(1):82–91.

Horn, S. D., R. A. Horn, and P. D. Sharkey. 1984. The severity of illness index as a severity adjustment to diagnosis-related groups. *Health Care Financing Review* 1984(Suppl):33-45.

HHS (US Department of Health and Human Services). 2014. *Healthy people 2020: Mental health and mental disorders.* Washington, DC: HHS. https://www.healthypeople.gov/2020/topics-objectives/topic/mental-health-and-mental-disorders (accessed October 31, 2017).

Jagsi, R., S. T. Hawley, P. Abrahamse, Y. Li, N. K. Janz, J. J. Griggs, C. Bradley, J. J. Graff, A. Hamilton, and S. J. Katz. 2014. Impact of adjuvant chemotherapy on long-term employment of survivors of early-stage breast cancer. *Cancer* 120(12):1854–1862.

Jang, D. B., S. D. Shin, Y. S. Ro, K. J. Song, K. O. Ahn, S. S. Hwang, Y. T. Kim, S. O. Hong, and J. A. Choi. 2016. Interaction of the diabetes mellitus and cardiac diseases on survival outcomes in out-of-hospital cardiac arrest. *American Journal of Emergency Medicine* 34(4):702–707.

Jones, E., J. Pike, T. Marshall, and X. Ye. 2016. Quantifying the relationship between increased disability and health care resource utilization, quality of life, work productivity, health care costs in patients with multiple sclerosis in the US. *BMC Health Services Research* 16:294.

Josephs, J. S., J. A. Fleishman, P. T. Korthuis, R. D. Moore, and K. A. Gebo. 2010. Emergency department utilization among HIV-infected patients in a multisite multistate study. *HIV Medicine* 11(1):74–84.

Kerr, J. C., T. G. Stephens, J. J. Gibson, and W. A. Duffus. 2012. Risk factors associated with inpatient hospital utilization in HIV-positive individuals and relationship to HIV care engagement. *Journal of Acquired Immune Deficiency Syndromes* 60(2):173–182.

Kim, M. H., J. Lin, M. Hussein, and D. Battleman. 2009. Incidence and economic burden of suspected adverse events and adverse event monitoring during af therapy. *Current Medical Research and Opinion* 25(12):3037–3047.

Kimball, A. B., J. Schenfeld, N. A. Accortt, M. S. Anthony, K. J. Rothman, and D. Pariser. 2014. Incidence rates of malignancies and hospitalized infectious events in patients with psoriasis with or without treatment and a general population in the U.S.A.: 2005–09. *British Journal of Dermatology* 170(2):366–373.

Lee, S., A. B. Rothbard, and E. L. Noll. 2012. Length of inpatient stay of persons with serious mental illness: Effects of hospital and regional characteristics. *Psychiatric Services* 63(9):889–895.

Leschke, J., J. A. Panepinto, M. Nimmer, R. G. Hoffmann, K. Yan, and D. C. Brousseau. 2012. Outpatient follow-up and rehospitalizations for sickle cell disease patients. *Pediatric Blood Cancer* 58(3):406–409.

Lieberman, J. A., A. Z. Safferman, S. Pollack, S. Szymanski, C. Johns, A. Howard, M. Kronig, P. Bookstein, and J. M. Kane. 1994. Clinical effects of clozapine in chronic schizophrenia: Response to treatment and predictors of outcome. *American Journal of Psychiatry* 151(12):1744–1752.

Martin, G. S., D. M. Mannino, S. Eaton, and M. Moss. 2003. The epidemiology of sepsis in the United States from 1979 through 2000. *The New England Journal of Medicine* 348(16):1546–1554.

Masters, G. A., R. J. Baldessarini, D. Ongur, and F. Centorrino. 2014. Factors associated with length of psychiatric hospitalization. *Comprehensive Psychiatry* 55(3):681–687.

McEnvoy, J. P., J. A. Lieberman, T. S. Stroup, S. M. Davis, H. Y. Meltzer, R. A. Rosenheck, M. S. Swartz, D. O. Perkins, R. S. Keefe, C. E. Davis, J. Severe, and J. K. Hsiao. 2006. Effectiveness of clozapine versus olanzapine, quetiapine, and risperidone in patients with chronic schizophrenia who did not respond to prior atypical antipsychotic treatment. *American Journal of Psychiatry* 163(4):600–610.

McKee, M. M., P. C. Winters, A. Sen, P. Zazove, and K. Fiscella. 2015. Emergency department utilization among deaf American sign language users. *Disability and Health Journal* 8(4):573–578.

McMorris, B. J., K. E. Downs, J. M. Panish, and R. Dirani. 2010. Workplace productivity, employment issues, and resource utilization in patients with bipolar I disorder. *Journal of Medical Economics* 13(1):23–32.

Menendez, M. E., and D. Ring. 2015. Factors associated with hospital admission for proximal humerus fracture. *American Journal of Emergency Medicine* 33(2):155–158.

Mizutani, K., M. Hara, S. Iwata, T. Murakami, T. Shibata, M. Yoshiyama, T. Naganuma, F. Yamanaka, A. Higashimori, N. Tada, K. Takagi, M. Araki, H. Ueno, M. Tabata, S. Shirai, Y. Watanabe, M. Yamamoto, and K. Hayashida. 2017. Elevation of b-type natriuretic peptide at discharge is associated with 2-year mortality after transcatheter aortic valve replacement in patients with severe aortic stenosis: Insights from a multicenter prospective ocean-tavi (optimized transcatheter valvular intervention-transcatheter aortic valve implantation) registry. *Journal of the American Heart Association* 6(7).

Moraska, A. R., A. M. Chamberlain, N. D. Shah, K. S. Vickers, T. A. Rummans, S. M. Dunlay, J. A. Spertus, S. A. Weston, S. M. McNallan, M. M. Redfield, and V. L. Roger. 2013. Depression, healthcare utilization, and death in heart failure: A community study. *Circulation: Heart Failure* 6(3):387–394.

Muehrer, R. J., D. Schatell, B. Witten, R. Gangnon, B. N. Becker, and R. M. Hofmann. 2011. Factors affecting employment at initiation of dialysis. *Clinical Journal of the American Society of Nephrology* 6(3):489–496.

Mujahid, M. S., N. K. Janz, S. T. Hawley, J. J. Griggs, A. S. Hamilton, and S. J. Katz. 2010. The impact of sociodemographic, treatment, and work support on missed work after breast cancer diagnosis. *Breast Cancer Research and Treatment* 119(1):213–220.

Mullady, D. K., D. Yadav, S. T. Amann, M. R. O'Connell, M. M. Barmada, G. H. Elta, J. M. Scheiman, E. J. Wamsteker, W. D. Chey, M. L. Korneffel, B. M. Weinman, A. Slivka, S. Sherman, R. H. Hawes, R. E. Brand, F. R. Burton, M. D. Lewis, T. B. Gardner, A. Gelrud, J. DiSario, J. Baillie, P. A. Banks, D. C. Whitcomb, M. A. Anderson, and N. Consortium. 2011. Type of pain, pain-associated complications, quality of life, disability and resource utilisation in chronic pancreatitis: A prospective cohort study. *Gut* 60(1):77–84.

Mullerova, H., D. J. Maselli, N. Locantore, J. Vestbo, J. R. Hurst, J. A. Wedzicha, P. Bakke, A. Agusti, and A. Anzueto. 2015. Hospitalized exacerbations of COPD: Risk factors and outcomes in the eclipse cohort. *Chest* 147(4):999–1007.

Munir, F., J. Yarker, and H. McDermott. 2009. Employment and the common cancers: Correlates of work ability during or following cancer treatment. *Occupational Medicine (Oxford, England)* 59(6):381–389.

Myer, P. A., A. Mannalithara, G. Singh, G. Singh, P. J. Pasricha, and U. Ladabaum. 2013. Clinical and economic burden of emergency department visits due to gastrointestinal diseases in the United States. *American Journal of Gastroenterology* 108(9):1496–1507.

Nadjiri, J., J. Hausleiter, S. Deseive, A. Will, E. Hendrich, S. Martinoff, and M. Hadamitzky. 2016. Prognostic value of coronary CT angiography in diabetic patients: A 5-year follow up study. *International Journal of Cardiovascular Imaging* 32(3):483–491.

Naz, B., T. J. Craig, E. J. Bromet, S. J. Finch, L. J. Fochtmann, and G. A. Carlson. 2007. Remission and relapse after the first hospital admission in psychotic depression: A 4-year naturalistic follow-up. *Psychological Medicine* 37(8):1173–1181.

NCHS. 2017a. *Health, United States, 2016: With chartbook on long-term trends in health*. Hyattsville, MD: National Center for Health Statistics.

NCHS. 2017b. National Health Interview Survey (NHIS) 2015 Data. https://www.cdc.gov/asthma/most_recent_data.htm (accessed October 31, 2017).

Nemunaitis, G., M. J. Roach, J. Claridge, and M. Mejia. 2016. Early predictors of functional outcome after trauma. *PM&R: The Journal of Injury, Function, and Rehabilitation* 8(4):314–320.

NHLBI (National Heart, Lung, and Blood Institute). 2012. *National Heart, Lung, and Blood Institute fact book: Chapter 4–disease statistics.* Washington, DC: HHS. https://www.nhlbi.nih.gov/about/documents/factbook/2012/chapter4 (accessed October 31, 2017).

NIDCD (National Institute on Deafness and Other Communication Disorders). 2016. *Quick statistics about hearing.* Bethesda, MD: NIH. https://www.nidcd.nih.gov/health/statistics/quick-statistics-hearing (accessed October 31, 2017).

NORC (National Opinion Research Center). 2013. *The economic burden of vision loss and eye disorders in the United States.* Bethesda, MD: NORC. https://www.preventblindness.org/sites/default/files/national/documents/Economic%20Burden%20of%20Vision%20Final%20Report_130611.pdf (accessed October 31, 2017).

O'Donnell, M. L., T. Varker, A. C. Holmes, S. Ellen, D. Wade, M. Creamer, D. Silove, A. McFarlane, R. A. Bryant, and D. Forbes. 2013. Disability after injury: The cumulative burden of physical and mental health. *Journal of Clinical Psychiatry* 74(2):e137–e143.

Omachi, T. A., E. H. Yelin, P. P. Katz, P. D. Blanc, and M. D. Eisner. 2008. The COPD severity score: A dynamic prediction tool for health-care utilization. *Journal of Chronic Obstructive Pulmonary Disease* 5(6):339–346.

Palma, A., D. W. Lounsbury, L. Messer, and E. B. Quinlivan. 2015. Patterns of HIV service use and HIV viral suppression among patients treated in an academic infectious diseases clinic in North Carolina. *AIDS and Behavior* 19(4):694–703.

Panopalis, P., J. Z. Gillis, J. Yazdany, L. Trupin, A. Hersh, L. Julian, L. A. Criswell, P. Katz, and E. Yelin. 2010. Frequent use of the emergency department among persons with systemic lupus erythematosus. *Arthritis Care and Research: The Official Journal of the Arthritis Health Professions Association* 62(3):401–408.

Parker, S. E., C. T. Mai, M. A. Canfield, R. Rickard, Y. Wang, R. E. Meyer, P. Anderson, C. A. Mason, J. S. Collins, R. S. Kirby, and A. Correa. 2010. Updated national birth prevalence estimates for selected birth defects in the United States, 2004–2006. *Birth Defects Research. Part A, Clinical and Molecular Teratology* 88(12):1008–1016.

Parsons, H. M., E. B. Habermann, S. C. Stain, S. M. Vickers, and W. B. Al-Refaie. 2012. What happens to racial and ethnic minorities after cancer surgery at American College of Surgeons national surgical quality improvement program hospitals? *Journal of the American College of Surgeons* 214(4):539–547; discussion 547–549.

Pendleton, A. M., L. K. Cannada, and M. Guerrero-Bejarano. 2007. Factors affecting length of stay after isolated femoral shaft fractures. *Journal of Trauma and Acute Care Surgery* 62(3):697–700.

Reichard, A. A., S. Konda, and L. L. Jackson. 2015. Occupational burns treated in emergency departments. *American Journal of Industrial Medicine* 58(3):290–298.

Reilly, M. C., A. Bracco, J. F. Ricci, J. Santoro, and T. Stevens. 2004. The validity and accuracy of the work productivity and activity impairment questionnaire—irritable bowel syndrome version (WPAI:Ibs). *Alimentary Pharmacology & Therapeutics* 20(4):459–467.

Rosenheck, R. A., S. E. Estroff, K. Sint, H. Lin, K. T. Mueser, D. G. Robinson, N. R. Schooler, P. Marcy, and J. M. Kane. 2017. Incomes and outcomes: Social Security disability benefits in first-episode psychosis. *American Journal of Psychiatry*. https://ajp.psychiatryonline.org/doi/10.1176/appi.ajp.2017.16111273 (accessed March 22, 2018).

Schofield, D., R. Shrestha, R. Percival, M. Passey, E. Callander, and S. Kelly. 2013. The personal and national costs of CVD: Impacts on income, taxes, government support payments and GDP due to lost labour force participation. *International Journal of Cardiology* 166(1):68–71.

Short, P. F., J. J. Vasey, and K. Tunceli. 2005. Employment pathways in a large cohort of adult cancer survivors. *Cancer* 103(6):1292–1301.

Short, P. F., J. J. Vasey, and R. Belue. 2008. Work disability associated with cancer survivorship and other chronic conditions. *Psychooncology* 17(1):91–97.

Siebert, U., J. Wurm, R. M. Gothe, M. Arvandi, S. R. Vavricka, R. von Kanel, S. Begre, M. C. Sulz, C. Meyenberger, and M. Sagmeister. 2013. Predictors of temporary and permanent work disability in patients with inflammatory bowel disease: Results of the Swiss inflammatory bowel disease cohort study. *Inflammatory Bowel Diseases* 19(4):847–855.

Simpson, D. R., M. E. Martinez, S. Gupta, J. Hattangadi-Gluth, L. K. Mell, G. Heestand, P. Fanta, S. Ramamoorthy, Q. T. Le, and J. D. Murphy. 2013. Racial disparity in consultation, treatment, and the impact on survival in metastatic colorectal cancer. *Journal of the National Cancer Institute* 105(23):1814–1820.

Sin, D. D., T. Stafinski, Y. C. Ng, N. R. Bell, and P. Jacobs. 2002. The impact of chronic obstructive pulmonary disease on work loss in the United States. *American Journal of Respiratory and Critical Care Medicine* 165(5):704–707.

SSA (Social Security Administration). 2015. *Annual statistical report on the Social Security Disability Insurance program, 2014.* Woodlawn, MD: SSA. https://www.ssa.gov/policy/docs/statcomps/di_asr/2014/index.html (accessed May 27, 2017).

SSA. 2017a. *Substantial gainful activity.* https://www.ssa.gov/oact/cola/sga.html (accessed May 27, 2017).

SSA. 2017b. *Disability evaluation under Social Security: Listing of impairments-adult listings (part A).* Woodlawn, MD: SSA. https://www.ssa.gov/disability/professionals/bluebook/AdultListings.htm (accessed March 1, 2017).

SSA. 2017c. *Di 90070.050 adjudicating a claim involving drug addiction or alcoholism (DAA).* https://secure.ssa.gov/poms.nsf/lnx/0490070050 (accessed December 13, 2017).

Stephens, R. J., S. E. White, M. Cudnik, and E. S. Patterson. 2014. Factors associated with longer length of stay for mental health emergency department patients. *Journal of Emergency Medicine* 47(4):412–419.

Suaya, J. A., R. M. Mera, A. Cassidy, P. O'Hara, H. Amrine-Madsen, S. Burstin, and L. G. Miller. 2014. Incidence and cost of hospitalizations associated with staphylococcus aureus skin and soft tissue infections in the United States from 2001 through 2009. *BMC Infectious Diseases* 14:296.

Thomas, K. L., A. F. Hernandez, D. Dai, P. Heidenreich, G. C. Fonarow, E. D. Peterson, and C. W. Yancy. 2011. Association of race/ethnicity with clinical risk factors, quality of care, and acute outcomes in patients hospitalized with heart failure. *American Heart Journal* 161(4):746–754.

Thorpe, R. J., Jr., A. J. Wynn, J. L. Walker, J. R. Smolen, M. P. Cary, S. L. Szanton, and K. E. Whitfield. 2016. Relationship between chronic conditions and disability in African American men and women. *Journal of the National Medical Association* 108(1):90–98.

Towfighi, A., D. Markovic, and B. Ovbiagele. 2011. National gender-specific trends in myocardial infarction hospitalization rates among patients aged 35 to 64 years. *American Journal of Cardiology* 108(8):1102–1107.

Tulloch, A. D., P. Fearon, and A. S. David. 2011. Length of stay of general psychiatric inpatients in the United States: Systematic review. *Administration and Policy in Mental Health and Mental Health Services Research* 38(3):155–168.

Tulloch, A. D., M. R. Khondoker, P. Fearon, and A. S. David. 2012. Associations of homelessness and residential mobility with length of stay after acute psychiatric admission. *BMC Psychiatry* 12:121.

Ueda, T., R. Kawakami, Y. Sugawara, S. Okada, T. Nishida, K. Onoue, T. Soeda, S. Okayama, Y. Takeda, M. Watanabe, H. Kawata, S. Uemura, and Y. Saito. 2014. Worsening of renal function during 1 year after hospital discharge is a strong and independent predictor of all-cause mortality in acute decompensated heart failure. *Journal of the American Heart Association* 3(6):e001174.

Virtanen, M., M. Kivimaki, J. Vahtera, M. Elovainio, R. Sund, P. Virtanen, and J. E. Ferrie. 2006. Sickness absence as a risk factor for job termination, unemployment, and disability pension among temporary and permanent employees. *Occupational and Environmental Medicine* 63(3):212–217.

Wahlqvist, P., M. Karlsson, D. Johnson, J. Carlsson, S. C. Bolge, and M. A. Wallander. 2008. Relationship between symptom load of gastro-oesophageal reflux disease and health-related quality of life, work productivity, resource utilization and concomitant diseases: Survey of a US cohort. *Alimentary Pharmacology & Therapeutics* 27(10):960–970.

Wolff, J., P. McCrone, A. Patel, K. Kaier, and C. Normann. 2015. Predictors of length of stay in psychiatry: Analyses of electronic medical records. *BMC Psychiatry* 15:238.

Wolfson, J. A., S. M. Schrager, T. D. Coates, and M. D. Kipke. 2011. Sickle-cell disease in California: A population-based description of emergency department utilization. *Pediatric Blood & Cancer* 56(3):413–419.

Woolf, A. D., and B. Pfleger. 2003. Burden of major musculoskeletal conditions. *Bulletin of the World Health Organization* 81(9):646–656.

Yabroff, K. R., W. F. Lawrence, S. Clauser, W. W. Davis, and M. L. Brown. 2004. Burden of illness in cancer survivors: Findings from a population-based national sample. *Journal of the National Cancer Institute* 96(17):1322–1330.

Yamada, S., Y. Shimizu, M. Suzuki, and T. Izumi. 2012. Functional limitations predict the risk of rehospitalization among patients with chronic heart failure. *Circulation Journal* 76(7):1654–1661.

Yazdany, J., B. J. Marafino, M. L. Dean, N. S. Bardach, R. Duseja, M. M. Ward, and R. A. Dudley. 2014. Thirty-day hospital readmissions in systemic lupus erythematosus: Predictors and hospital- and state-level variation. *Arthritis & Rheumatology* 66(10):2828–2836.

Yehia, B. R., J. A. Fleishman, P. L. Hicks, M. Ridore, R. D. Moore, and K. A. Gebo. 2010. Inpatient health services utilization among HIV-infected adult patients in care 2002–2007. *Journal of Acquired Immune Deficiency Syndromes* 53(3):397–404.

Young, A. E., M. Cifuentes, R. Wasiak, and B. S. Webster. 2009. Urban-rural differences in work disability following occupational injury: Are they related to differences in healthcare utilization? *Journal of Occupational and Environmental Medicine* 51(2):204–212.

Young, A., S. Muhlner, A. Kurowski, and M. Cifuentes. 2015. The association between physical medicine and rehabilitation service utilization and disability duration following work-related fracture. *Work* 51(2):327–336.

Zhang, J., C. Harvey, and C. Andrew. 2011. Factors associated with length of stay and the risk of readmission in an acute psychiatric inpatient facility: A retrospective study. *Australian & New Zealand Journal of Psychiatry* 45(7):578–585.

5

Proxies for Determining Listing-Level Severity

To assess whether health-care utilization is a good proxy for listing-level severity, the committee examines, in this chapter, what would make a good proxy. The starting point is that a good proxy for a health-care utilization or a combination of health-care utilizations would correctly classify people as having "listing-level severity" or "no listing-level severity" in a sufficiently large proportion of cases. Listing-level severity is defined in step 3 of the disability-determination process (see Chapter 1) as referring to an impairment that would qualify a person for Social Security Disability Insurance (SSDI). This chapter examines the characteristics of "classifiers" of listing-level severity and discusses the elements of a study that might predict utilizations that would be proxies for listing-level severity.

HEALTH-CARE UTILIZATIONS FOR CONSTRUCTING CLASSIFIERS OF LISTING-LEVEL SEVERITY

A set of health-care utilizations that can be used for classification of people as having listing-level severity or no listing-level severity might be defined as a classifier. An example of a classifier that is used in a number of the Social Security Administration (SSA) Listings to determine listing-level severity is "3 hospitalizations in the previous year occurring at least 30 days apart." Thus, a person who has three or more such hospitalizations is classified as positive for having listing-level severity, and a person who has fewer than three hospitalizations is classified as negative for having listing-level severity. That classifier is admittedly simplistic in that it relies on a single type of health-care utilization (hospitalizations). Its use in isolation might not be optimal for accurate classification of people as having or not having listing-level severity. However, its simplicity facilitates our description of the main concepts below. The concepts can then be readily applied to more realistic classifiers that combine multiple health-care utilization measures.

CHARACTERISTICS OF CLASSIFIERS

As represented in Table 5-1, each person who is subject to the application of a classifier will end up in one of four categories: true positive, false positive, true negative, or false negative. In this context, a false positive results when a person who has no listing-level severity is

incorrectly classified as having listing-level severity (because the impairment is not severe enough to result in an inability to participate in any gainful activity). Similarly, a false negative results when a person who has listing-level severity is incorrectly classified as not having listing-level severity.

TABLE 5-1 The Four Categories of People in a Binary Classification Problem

		True Status	
		Listing-level severity	**No listing-level severity**
Classifier Result	**Positive**	True positives	False positives
	Negative	False negatives	True negatives

Any study conducted to evaluate a classifier would require enough data to classify all people into one of the four cells of Table 5-1. That requirement implies that a standard of listing-level severity needs to be developed so that the true status of every person in a study is known. Ascertaining true status might be expensive or labor-intensive if it requires, for example, independent medical consultations with each disability applicant. However, an assumption will be made that the true status of each person in the study is known.

Ideally, a classifier by which the proportion of people who are classified as positive (i.e., who have listing-level severity) is 100 percent [(true positives)/(true positives + false positives) = 1.00] is known to have *positive predictive value*. Similarly, a classifier by which the proportion of people who are classified as negative (i.e., who do not have listing-level severity) is 100 percent [(true negatives)/(false negatives + true negatives) = 1.00] is known to have *negative predictive value*.

The positive predictive value depends on both the prevalence of listing-level disability in the pool of applicants and the discriminatory power of the classifier. The standard approach to evaluating the discriminatory power of a classifier is to calculate its *sensitivity*, the proportion of people who are positive among those who have listing-level severity [(true positives)/(true positives + false negatives)], and *specificity*, the proportion of people who are negative among those who do not have listing-level severity [(true negatives)/(false positives + true negatives)]. No classifier can have 100 percent sensitivity (zero false negatives) and 100 percent specificity (zero false positives). All classifiers make errors in discerning false positives and false negatives. Therefore, in choosing among classifiers, there is a need to make tradeoffs regarding the relative importance of those errors. Figure 5-1 illustrates the tradeoffs between false negatives and false positives for a classifier that is based exclusively on number of hospitalizations; the same logic would apply to any classifier.

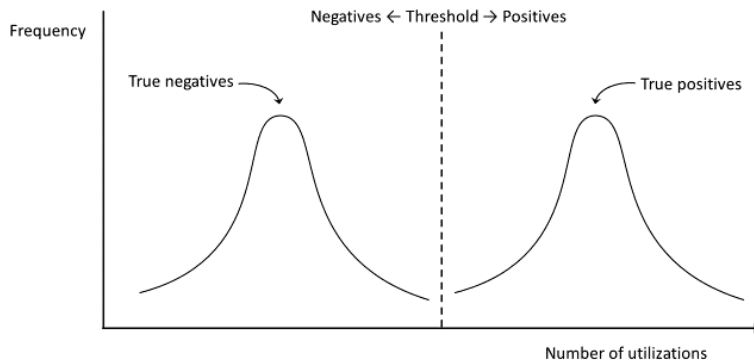## TRADEOFFS IN THE CLASSIFICATION OF LISTING-LEVEL SEVERITY

FIGURE 5-1 An ideal classifier.

Figure 5-1 shows a hypothetical distribution of the number of hospitalizations conditional on having listing-level severity (first curve) or not having listing-level severity (second curve), respectively. In that population, all nondisabled people have a number of health-care utilizations that is lower than a particular threshold (e.g., less than three hospitalizations), and all disabled people have three or more hospitalizations. As a result, the classifier "less than 3 hospitalizations" perfectly classifies all members of the population. That is, all disabled people are "true positives," all nondisabled are "true negatives," and there are no false positives or false negatives. However, Figure 5-1 represents an unrealistic situation in that no classifier is likely to separate disabled and nondisabled people perfectly.
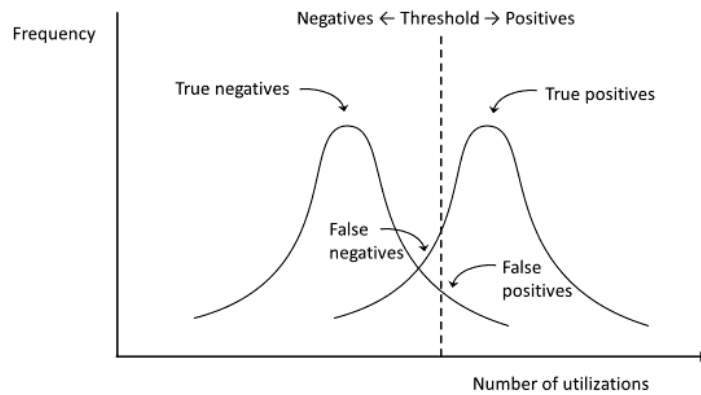
FIGURE 5-2 A real-world classifier.

Figure 5-2 represents the more common situation in which no threshold of health-care utilizations can perfectly discriminate the two groups. Therefore, the classifier of the form "less than 3 hospitalizations" will result in some nondisabled people incorrectly classified as disabled (false positives) and some disabled people incorrectly classified as nondisabled (false negatives). The choice of a different threshold will result in different proportions of false negatives and false

positives. For example, increasing the threshold to four hospitalizations will decrease the proportion of nondisabled that are false positives (and thereby increase specificity) and will decrease the proportion of disabled that are true positives (and thereby decrease sensitivity).

As Figure 5-2 shows, in a world with overlapping distributions of hospitalizations, one cannot reduce false positives without also reducing true positives, and vice versa.

The committee, for simplicity, has considered a unidimensional classifier, number of hospitalizations. In practice, one could consider multidimensional classifiers that are based on several measures of health-care utilization (as opposed to only number of hospitalizations). In fact, some proposed classifiers for medical conditions in the 21st century are based on hundreds or thousands of variables (e.g., variables obtained from insurance claims databases or electronic medical records) and take advantage of modern advances in machine learning algorithms. Regardless of the complexity of the classifier, it will rarely be able to provide a clean separation between disabled and nondisabled populations.

CHOICE OF CLASSIFIER AS A VALUE JUDGMENT

Inasmuch as any classifier has to find a balance between false positives and false negatives, the question is whether false positives and false negatives will be given the same weight or whether one of the two is considered more serious than the other. One would need to decide how to weigh false positives and false negatives in an effort to select a classifier.

In our setting, the classifier operates in the early steps of the screening process, and people who are classified as having listing-level severity (the positives) are automatically considered eligible and not considered further at later stages. In contrast, people who are classified as not having listing-level severity (the negatives) can be determined eligible at later stages. Therefore, from a societal point of view, a false positive might be viewed as a more expensive mistake than a false negative. A possible strategy might be to choose classifiers that err on the side of increasing false negatives rather than false positives, that is, classifiers that have higher specificity at the expense of lower sensitivity. However, the relative emphasis on the positive predictive value versus the negative predictive value depends on the goals of the classification. In any case, the decision to privilege false negatives over false positives, or vice versa, is a judgment that SSA would have to make.

Accordingly, a possible strategy might be to choose classifiers that err on the side of increasing false negatives rather than false positives, that is, classifiers that have higher specificity at the expense of lower sensitivity. In the simplified example of Figure 5-2, the threshold would be moved to the right (e.g., "less than 5 hospitalizations") to minimize the proportion of false positives, as shown in Figure 5-3.
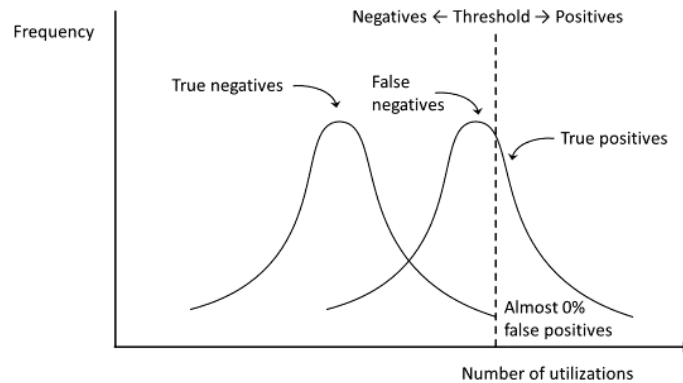
FIGURE 5-3 A classifier that minimizes the proportion of false positives.

A key challenge is that the positive predictive value depends critically on the prevalence of listing-level severity in the population of applicants who reach step 3. That is, even a classifier that has high discriminatory power, as measured by sensitivity and specificity, might have a low positive predictive value. For example, suppose that an excellent classifier that has 100 percent sensitivity and 90 percent specificity is developed. And suppose that the prevalence of listing-level severity among applicants is 20 percent, that is, only one-fifth of applicants are truly unable to do any gainful activity. Then it is easy to show that the positive predictive value will be only 71 percent. That is, using the almost implausibly good classifier, only 71 percent of people who are classified as having listing-level severity actually have listing-level severity. Thus, in that example, if 1 million applicants were evaluated according to the classifier, all 200,000 disabled applicants would be awarded benefits, but so would 80,000 nondisabled applicants.

All the above can be applied similarly to the negative predictive value, that is, the proportion of people who do not have listing-level severity among those who are classified as not having listing-level severity by the classifier. The relative emphasis on the positive predictive value versus the negative predictive value depends on the goals of the classification. Here, because of our context, we have focused on the positive predictive value.

The decision to privilege false negatives over false positives, or vice versa, is a judgment for SSA to make. The dependence of the positive (and negative) predictive value on both the classifier's discriminatory power and the true prevalence of listing-level severity raise fundamental questions, of which these are prominent:

1. What is the lowest positive (or negative) predictive value of a classifier that SSA is willing to tolerate for step 3?
2. Given the expected prevalence of true disability, what levels of sensitivity and specificity are required to achieve at least the lowest value tolerated by SSA?
3. Given the available data on health-care utilizations and state-of-the-art predictive techniques, is the development of a classifier with those sensitivity and specificity levels achievable?
4. If the answer to question 3 is no, can a more modest role of the use of health-care utilizations in the classification of listing-level severity be defined?

Answering those questions is instructive in assessing the likelihood that SSA will be able to use health-care utilizations for classification of listing-level disability. Answering question 1 involves a policy judgment. Question 2 will have an immediate answer as soon as an answer to question 1 is provided. Question 3 is an empirical question; answering it requires a research project to evaluate the performance of the classifier.

DESIGNING A STUDY

The performance of a health-care utilization or a combination of health-care utilizations as a classifier of SSDI applications is measured by its positive and negative predictive values for different cutoffs. Calculation of those values requires knowledge of the prevalence of listing-level severity among SSDI applicants who have a particular medical condition and of the distributions of health-care utilizations that are conditional on listing-level severity. That in turn requires knowledge of the true status (listing-level or non-listing-level severity) of each individual.

However, determining listing-level severity—defined by SSA as the inability to perform any gainful activity regardless of age, education, or work experience—is challenging. Observing that a person is not working does not necessarily mean that the person cannot work. Indeed, it has been noted, in some studies, that the disability-determination process itself provides applicants with a strong disincentive to work, inasmuch as any (substantial) gainful activity performed during or immediately before the application period can be used as evidence that the applicant can work (Maestas et al., 2013; Autor et al., 2015). At the same time, expert assessments of disability severity can be inaccurate and can lead to identification of some people who can work as unable and to identification of some who are unable to work as able. For some diagnoses, determination of listing-level disability might be straightforward because of the readily observed effects of the illness or disorder. For other diagnoses, determination of ability to work requires more subjective judgment, particularly for less visible sources of disability, such as impairments in cognition or emotional regulation and or chronic pain and fatigue.

Thus, a research design that compares health-care utilization distributions for applicants who equaled the Listings (and later manifested very low levels of post award work) with those who were denied at step 3 (and possibly allowed at step 5) could be used to approximate measures of sensitivity and specificity for various cutoff levels of health-care utilizations. Such a study could provide measures of the prevalence of listing-level severity among the population of interest. Of course, predictions that arise from any particular study will become outdated as the health system changes, and the study would need to be repeated periodically.

Together, those estimates could be used to determine the likelihood that calculation of positive (and negative) predictive prevalence would lead to mistaken listing-level severity for various candidate measures. If the accuracy of a prediction is sufficiently high, in the judgment of SSA, the health-care utilization could be considered an acceptable classifier for listing-level severity and could be incorporated into the Listing of Impairments.

One option is to confine interest to diagnoses for which expert assessment of listing-level severity is straightforward and reliant on objective measures. In those situations, expert assessment can be used as the gold standard with which health-care utilizations can be compared. However, when a disability is less readily observable, expert assessment alone might not constitute a gold standard and might need to be supplemented with additional information, such

as work outcomes. Another option could be to use data on health-care utilizations and listing-level severity in the context of a disability insurance program without strong work disincentives.

Yet another possibility could be to merge administrative records of past SSDI applications with data on health-care utilization history available at the time of determination and data on postdetermination work outcomes. Thus, disability examiners (and later administrative law judges) who adjudicated the cases would be the experts providing assessments. SSA administrative data contain the basis of all medical determinations, including separate codes for whether successful applicants at step 3 have impairments that "met" or "equaled" the Listing of Impairments. An applicant whose impairments are determined to "equal" a listing is determined to have listing-level severity but not specifically to meet the criteria laid out in the actual Listings (20 CFR §§ 404.1526 and 416.926). The ability to identify such cases as meeting a listing at step 3 of an initial determination could greatly decrease the time to determination, especially if it led to fewer appeals (and engagement of disability attorneys to make the case that an impairment equals a listing).

For example, at least 14 states have already developed all-payer claims databases (APCDs) that pool the information required for such analysis from both public and private insurers. Four more states are in the process of implementing an APCD, and 16 more states have shown strong interest in developing their own APCD. It is therefore possible that, in a few years, most states will have APCDs to conduct the proposed analysis.[1]

SUMMARY AND CONCLUSION

Inasmuch as there is scant literature on finding evidence of health-care utilizations that would be good proxies for listing-level disability, the committee considered the question, "What would make a good proxy?" That is, what proxy would result in the smallest number of false positives? Listing-level severity—defined by SSA as the inability to perform any gainful activity regardless of age, education, or work experience—is not easy to measure in practice. Simply observing that a person is not working does not necessarily mean that a person cannot work. Indeed, it has been noted, in some studies, that the disability-determination process itself provides applicants with a strong disincentive to work, inasmuch as any (substantial) gainful activity performed during or immediately before the application period can be used as evidence that the applicant can work. At the same time, expert assessments of disability severity will suffer from some level of type I and type II error.

Before developing a classifier, to improve assessments of disability, there would need to be decisions made about false positives and false negatives. From a societal point of view, a false positive might be viewed as a more expensive mistake than a false negative. A possible strategy might be to choose classifiers that err on the side of increasing false negatives rather than false positives, that is, classifiers that have higher specificity at the expense of lower sensitivity. However, the relative emphasis on the positive predictive value versus the negative predictive value depends on the goals of the classification. In any case, the decision to privilege false negatives over false positives, or vice versa, is a judgment that SSA would have to make.

Multiple issues should be explored in designing a study, such as confining interest to diagnoses for which expert assessment of listing-level severity is straightforward and reliant on objective measures, using data on health-care utilizations and listing-level severity in the context

---

[1]See https://www.apcdcouncil.org (accessed February 4, 2018) for details.

of a disability insurance program that does not have strong work disincentives, and merging administrative records of past SSDI applications with data on health-care utilizations history that are available at the time of a determination and data on postdetermination work outcome.

Given appropriate data, models for quantifying the value of health-care utilizations in determining impairment severity are available. However, given the rapidly changing health-care landscape, predictive models that are developed now might not have the same performance attributes later. Analyses will have to be repeated as the health-care landscape changes.

REFERENCES

Autor, D. H., N. Maestas, K. Mullen, and A. Strand. *Does Delay Cause Decay? The Effect of Administrative Decision Time on the Labor Force Participation and Earnings of Disability Applicants.* Santa Monica, CA: RAND Corporation, 2015. https://www.rand.org/pubs/working_papers/WR1070.html (accessed February 27, 2018).

Maestas, N., K. J. Mullen, and A. Strand. 2013. Does disability insurance receipt discourage work? Using examiner assignment to estimate causal effects of SSDI receipt. *American Economic Review* 103(5):1797−1829.

A

Health-Care Utilizations

This appendix identifies different types of health-care utilizations. Health-care utilizations can be delivered at sites and facilities or can involve the use of prescription drugs, durable and nondurable medical products, and so on. The Centers for Medicare & Medicaid Services (CMS) categorizes types of health-care services as follows (CMS, 2017):

- Hospital care
- Physician and clinical services
- Other professional services
- Dental services
- Home health care
- Other health, residential, and personal care
- Nursing care services
- Prescription drugs
- Other nondurable medical products
- Durable medical products

In general, a health-care service site or facility is any location where health care is provided. Health-care facilities might be privately owned as for-profit businesses, publically owned by local governments or the federal government (e.g., US Department of Veterans Affairs hospitals), or run as nonprofit organizations.

HOSPITALS

According to CMS, a hospital is an institution engaged primarily in providing, by or under the supervision of physicians, inpatient diagnostic and therapeutic services or rehabilitation services. Hospitals have medical and other professional staff and inpatient facilities. They deliver services 24 hours per day, 7 days per week. They might also include other services such as hospital-based nursing-home care, inpatient rehabilitation, and organ transplantation (CMS, 2007, 2014). Estimates of hospital utilization are based on various factors, including hospital discharge rates, admissions to the emergency department (ED), ED readmissions, length of stay, and percentage of population hospitalized.

The Social Security Administration (SSA), in its Listing of Impairments, includes number of hospitalizations as criteria for receiving disability insurance related to six body systems: respiratory, cardiovascular, digestive, genitourinary, hematologic, and immune. Those criteria require an applicant to have, for a particular medical condition or combination of conditions, "exacerbations or complications requiring three hospitalizations within a 12-month

period and at least 30 days apart" of which "each hospitalization must last at least 48 hours, including hours in a hospital ED immediately before the hospitalization."

PHYSICIAN AND CLINICAL SERVICES

Physician and clinical services include those rendered by doctors of medicine and doctors of osteopathy in inpatient and outpatient care centers, physician offices, and medical and diagnostic laboratory services (CMS, 2014). This category also comprises services rendered by physician assistants and nurses practicing in advanced practice registered nurse (APRN) roles, such as nurse practitioners, clinical nurse specialists, certified nurse-midwives, and certified registered nurse anesthetists. APRNs[1] have assumed an increasing role as providers in the health-care system throughout the United States. Many practice in retail clinics, which have increased by 47 percent since 2014 and will soon have the capacity to accommodate 25 million annual visits (Hempstead, 2017).

Practicing psychologists can help with social and mental health problems and use various evidence-based treatments. Therapy (often referred to as psychotherapy or talk therapy) includes cognitive, behavioral, cognitive–behavioral, interpersonal, humanistic, and psychodynamic therapy. It can be useful for individuals, couples, families, and other groups.

OTHER PROFESSIONAL SERVICES

Emergency Medical Services

Emergency medical services (EMS)—most commonly thought of as ambulance service but also including aeromedical and other prehospital services—constitutes another health-care utilization and plays a critical role in the health-care system by providing timely out-of-hospital emergency medical care (EMS.gov, 2017a). EMS is a coordinated and comprehensive system that works with various entities—including trauma centers, hospitals, and transportation networks—to provide emergency care (EMS.gov, 2017a). It is regarded as the first step in the spectrum of emergency care delivery by improving community health and providing prehospital care directly to patients who have acute illnesses and injuries (EMS.gov, 2017b).

Certified EMS providers respond to and treat more than 18 million patients annually in the United States (Meisel et al., 2011). Those people are first-responders who provide various services, including responses to 911 calls, prehospital acute medical care, stabilization, hospital transportation, and interfacility transport (IOM, 2007).

Ambulances—from government, fire or police, voluntary, private, or hospital-based entities—provide the most recognized type of EMS services (EMS.gov, 2017b). Some 14 percent of ED visits in 2003 were by patients who arrived by ambulance; these patients were more likely to be older, require emergency or urgent care, and be hospitalized (Burt et al., 2006). The most common reasons for patients to arrive by ambulance were chest pain and shortness of breath (Meisel et al., 2011).

---

[1] APRNs complete specialty-specific graduate programs that include education, training, and practice experience needed to complete a national board certification examination before entry into practice.

DENTAL SERVICES

Dental services are concerned with treating the teeth and associated structures of the oral cavity, including prevention diagnosis of, treatment for disease, and restoration of defective or missing teeth. A recent article in the *Journal of Dental Education* notes that there has been a remarkable decline in dental caries in the United States, which has resulted in substantial declines in the use of reparative and restorative dental services. Because fewer teeth are compromised, extractions and their sequelae are also declining, and periodontal maintenance care can be provided by allied dental personnel (Eklund, 2017).

HOME HEALTH CARE

Home health care is the provision of services to people in their homes. Most home health-care patients are elderly. According to the US Department of Health and Human Services, direct care workers—such as nurse aides, home health aides, and home-care aides—are the primary providers of paid care for more than 13 million elderly and disabled Americans. They assist with a broad array of support, such as preparing meals, helping with medications, bathing, and dressing. Direct care workers constitute one of the largest and fastest-growing sectors of the workforce. The chronically ill, terminally ill, and disabled are those most likely to use such services, which include, for example, homemaker services, intravenous administration of antibiotics, transfusion therapy, infusion therapy, chemotherapy, dialysis, enteral and parenteral nutrition, and long-term oxygen therapy (NCHS, 2003).

OTHER TYPES OF HEALTH-CARE UTILIZATIONS

The committee notes here a few other types of facilities and programs, although with some exceptions data on these are scarce or nonexistent. The committee thought it important to include them, however, as they might indicate other types of health-care utilization to be considered by SSA.

Workplace Site

According to the National Association of Worksite Health Centers (NAWHC), workplace "onsite clinics" are settings where employers offer medical and wellness services delivered by licensed providers to all or a designated portion of their active populations and other eligible people. Such clinics are typically referred to as health and wellness centers because of the wide variety of first aid, occupational health, acute, primary, specialty, condition management, wellness, and other services offered.

Workplace programs are often part of the health benefit options that employers offer to their workers. The objective is to provide easy access and immediate attention, at little or no cost, for a host of services and products that an employee would normally have to leave the workplace to obtain (NAWHC, 2017).

Employee Assistance Programs (EAPs) are voluntary, work-based programs that offer free and confidential assessments, short-term counseling, referrals, and followup services to employees who have personal or work-related problems. EAPs address a broad array of complex

issues, including mental and emotional well-being, such as alcohol and other substance abuse, stress, grief, family problems, and psychologic disorders. EAP counselors also consult with managers and supervisors to address employee and organizational challenges and needs. Many EAPs are active in helping organizations to prevent and cope with workplace violence, trauma, and other emergency response situation (OPM, 2017).

Urgent Care

Urgent care facilities—as distinct from hospitals, physicians' offices, and clinics—provide basic medical care for unscheduled, ambulatory patients who are seeking immediate medical attention (CMS, 2015). Unlike emergency departments, urgent care facilities typically are not open 24 hours per day. Basic medical care includes diagnoses that do not require advanced laboratory imaging and treatments that do not require complex procedures (Mehrotra et al., 2009).

Utilization of urgent care facilities has increased in recent years as an alternative to ED, hospital, and clinic visits, but their clinical efficacy remains unclear. A recent Cochrane systematic review found no controlled-trial evidence on the quality of care provided by urgent-care facilities (Chen et al., 2017).

Day Centers for Severe Mental Illness

The National Alliance on Mental Illness notes that the treatment setting for mental health varies from physicians' offices to community or county mental health centers. A community or county mental health care center can provide public mental health care services when a referral to a private doctor or therapist is not possible. Centers are operated by local governments to meet the needs of people whose mental health condition seriously affects their daily functioning. Services that a person might receive from a community or county mental health center include psychiatry, outpatient services, medication management, case-management services, intensive community treatment services, and help with employment and substance-use issues. Psychiatrists, psychologists, social workers, counselors, and peer-support specialists work at centers to provide the various services that clients need.

A 2005 World Health Organization report examined five main forms of day care for adults who have severe mental health disorders. It notes that the evidence on different forms of day care services for such peoples is not easy to interpret (WHO, 2005).

Substance-Abuse Treatment Centers

Some people who have mental health conditions might also have substance-abuse problems. The most widely used form of treatment is integrated intervention, in which a person receives care for both a specific mental illness and substance abuse. Types of substance-abuse centers include detoxification facilities, acute residential treatment programs, and intensive outpatient programs (NAMI, 2017).

Assisted-Living Facilities

Assisted-living facilities provide a wide variety of supportive services, such as housekeeping and transportation, to people who want to maintain some level of independence but require support in activities of daily living. They might have apartment-style living on

grounds where community health workers or aides help with such activities as laundry, baths, cooking, and shopping. Assisted-living facilities are not as highly regulated as skilled nursing facilities (SNFs). They are paid for privately and have no limitations on length of stay (Mitty and Flores, 2007).

SKILLED NURSING FACILITIES

SNFs provide a high level of medical care through a team of trained people that might include registered nurses (RNs), social workers, psychiatrists, dietitians, and physical, speech, and occupational therapists. Such services can be rendered over the short term for rehabilitation purposes or over the long term for patients who need frequent or around-the-clock care because of chronic medical conditions (Garcia et al., 2016). Typically, SNFs involve short-stay high-intensity care in a long-term care setting, such as a nursing home. The short-term stay is often paid for by Medicare for up to 90 days. If medically necessary, stays might be extended into long-term care paid through Medicaid or private payers with no limits in length of stay, depending on state and federal benefit regulations.

PRESCRIPTION DRUGS

Prescription drugs are pharmaceutical agents that are used to prevent or delay the onset of chronic disease and disability, control or cure disease, and provide relief from pain (NCHS, 2014).

From 2007 to 2010, almost half the US population took at least one prescription drug in the preceding month and one-tenth reported taking five or more drugs. According to the National Center for Health Statistics, Americans' use of prescription drugs has grown over the past half-century for a variety of reasons, such as the development of new and innovative drug therapies, the expansion of prescription drug coverage by public and private payers, and increased marketing by pharmaceutical companies.

Prescription drug development in the second half of the 20th century has focused on chronic diseases, such as cancer, heart disease, diabetes, and mental health disorders. Drugs that treat those conditions were among the most commonly used by adults. The widespread use of chemotherapy and other biologics contributed to raising 5-year cancer survival rates to 67 percent in 2009 (NCHS, 2014). Drugs for heart disease have led to better treatment and control of the risk factors for heart disease, and prescription drugs are an important component in the treatment of mental health disorders.

DURABLE AND NONDURABLE MEDICAL PRODUCTS

Durable medical products are defined by CMS as reusable or nondisposable medical equipment that serves a medical purpose and is appropriate for use in the home. They include hospital beds, wheelchairs, walkers, canes, commode chairs, blood pressure and blood glucose monitors, orthopedic products, hearing aids, and home oxygen equipment (CMS, 2014). Nondurable medical products are medical supplies that can be discarded after use. Examples include examination gloves, needles, and surgical instruments, such as surgical dressings (CMS, 2014).

REFERENCES

Burt, C. W., L. F. McCaig, and R. H. Valverde. 2006. Analysis of ambulance transports and diversions among US emergency departments. *Annals of Emergency Medicine* 47(4):317–326.

Chen, C. E., C. T. Chen, J. Hu, and A. Mehrotra. 2017. Walk-in clinics versus physician offices and emergency rooms for urgent care and chronic disease management. *The Cochrane Database of Systematic Reviews* 2:CD011774.

CMS (Centers for Medicare & Medicaid Services). 2007. *CMS manual system pub 100-04 Medicare claims processing: New web site for approved transplant centers.* Washington, DC: CMS. https://www.cms.gov/Regulations-and-Guidance/Guidance/Transmittals/downloads/R1341CP.pdf (accessed May 25, 2017).

CMS. 2014. National health expenditures accounts: Methodology paper, 2014. In *Definitions, Sources, and Methods.* Washington, DC: CMS. https://www.cms.gov/research-statistics-data-and-systems/statistics-trends-and-reports/nationalhealthexpenddata/downloads/dsm-14.pdf (accessed May 25, 2017).

CMS. 2015. *CMS manual system pub 100-04 Medicare claims processing: New and revised place of service codes (POS) for outpatient hospital.* Washington, DC: CMS. https://www.cms.gov/Regulations-and-Guidance/Guidance/Transmittals/downloads/R3315CP.pdf (accessed May 25, 2017).

CMS. 2017. *Projections of national health expenditures: Methodology and model specification.* Washington, DC: CMS. https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/NationalHealthExpendData/downloads/projectionsmethodology.pdf (accessed May 25, 2017).

Eklund, S. A. 2017. The impact of improved oral health on the utilization of dental services. *Journal of Dental Education* 81(8):eS110–eS119.

EMS.gov. 2017a. *What is EMS?* https://www.ems.gov/whatisems.html (accessed November 8, 2017).

EMS.gov. 2017b. *National EMS scope of practice model.* https://www.ems.gov/education/EMSScope.pdf (accessed November 8, 2017).

Garcia, T. J., T. C. Harrison, and J. S. Goodwin. 2016. Nursing home stakeholder views of resident involvement in medical care decisions. *Qualitative Health Research* 26(5):712–728.

Hempstead, K. 2017. *How is health care utilization changing?* https://www.cms.gov/Research-Statistics-Data-and-Systems/Research/ActuarialStudies/Downloads/MedicaidReport2016.pdf (accessed November 7, 2017).

IOM (Institute of Medicine). 2007. *Emergency medical services: At the crossroads.* Washington, DC: The National Academies Press.

Mehrotra, A., H. Liu, J. L. Adams, M. C. Wang, J. R. Lave, N. M. Thygeson, L. I. Solberg, and E. A. McGlynn. 2009. Comparing costs and quality of care at retail clinics with that of other medical settings for 3 common illnesses. *Annals of Internal Medicine* 151(5):321–328.

Meisel, Z. F., J. M. Pines, D. Polsky, J. P. Metlay, M. D. Neuman, and C. C. Branas. 2011. Variations in ambulance use in the United States: The role of health insurance. *Academic Emergency Medicine* 18(10):1036–1044.

Mitty, E., and S. Flores. 2007. Assisted living nursing practice: Medication management: Part 1. Assessing the resident for self-medication ability. *Geriatric Nursing* 28(2):83–89.

NAMI (National Alliance on Mental Illness). 2017. *Treatment settings.* https://www.nami.org/Learn-More/Treatment/Treatment-Settings (accessed November 8, 2017).

NAWHC (National Association of Worksite Health Centers). 2017. *What is an onsite clinic?* https://www.nawhc.org/about-nawhc/what-onsite-clinic (accessed May 27, 2017).

NCHS (National Center for Health Statistics). 2003. *Healthcare in America: Trends in utilization.* Hyattsville, MD: HHS (US Department of Health and Human Services). https://www.cdc.gov/nchs/data/misc/healthcare.pdf (accessed March 1, 2017).

NCHS. 2014. Health, United States. In *Health, United States, 2013: With special feature on prescription drugs*. Hyattsville (MD): National Center for Health Statistics (US).

OPM (Office of Personnel Management). 2017. *Work-life: Employee assistance programs*. https://www.opm.gov/policy-data-oversight/worklife/employee-assistance-programs (accessed May 27, 2017).

WHO (World Health Organization). 2005. *How effective are different types of day care services for people with severe mental disorders?* Copenhagen, Denmark: WHO Regional Office for Europe.

B

Evidence Review Strategy

This appendix presents the committee's approach to identifying and evaluating the scientific literature reviewed in addressing the committee's statement of task. In addressing its task of identifying types of health-care utilizations that might be good proxies for "listing-level" severity and examining factors that affect the use of health-care services, committee members collaborated with staff to identify key words, and to define and refine the search strategy. The committee used an iterative process in conducting the literature searches. In total, the committee and staff screened more than 60,000 articles from the peer-reviewed scientific literature and selected 708 for careful review. Additionally, for background information and to address the task order objective of providing a general description of the health-care delivery system, the committee searched relevant government and nongovernment research organization websites. The committee's search included papers published in the past 10 years.

The committee's search strategies are described in this appendix.

LITERATURE SEARCH STRATEGY: HEALTH-CARE UTILIZATIONS AS PROXIES FOR IMPAIRMENT SEVERITY

In January 2016, the PubMed database was searched using a combination of key words related to health-care utilizations, impairment severity, and disability.

Key words searched in combination with the National Library of Medicine's Medical Subject Headings (MeSH) keywords for each body system in the Social Security Administration's Listing of Impairments included

- "Health care utilization"[All Fields] OR "Healthcare utilization"[All Fields]
- "Hospitalization"[Mesh] OR ("Emergency Service, Hospital/statistics and numerical data"[Mesh] OR "Emergency Service, Hospital/trends"[Mesh] OR "Emergency Service, Hospital/utilization"[Mesh])
- ("Disabled Persons/nursing"[Mesh] OR "Disabled Persons/rehabilitation"[Mesh] OR "Disabled Persons/standards"[Mesh] OR "Disabled Persons/statistics and numerical data"[Mesh] OR "Disabled Persons/surgery"[Mesh] OR "Disabled Persons/therapy"[Mesh] OR "Disabled Persons/trends"[Mesh] OR "Disabled Persons/utilization"[Mesh])

Additionally, the following key words were searched without combining with MeSH terms for body systems:

- "Work disability"[All Fields]
- ("Primary Health Care/utilization"[Mesh] AND "Chronic Disease"[Mesh])

The following filters were applied:

- Last 10 years (ending February 13, 2017)
- English language
- Adults 19 through 65 years of age

The initial search resulted in 36,606 papers. The staff's screening resulted in a final count of 800 papers.

Staff screened papers for relevance to the statement of task. The following topics were screened in:

- Affordable Care Act
- Disability
- Disparities in health care (diagnosis, admissions, treatment, etc.)
- Factors that affect return to work
- Functional status
- Gender disparities
- Health care laws
- Health care utilizations
- Hospital utilizations
- Hospitalizations
- Length of stay
- Measures of disability
- Medicare/Medicaid
- Predictors of disease severity/Measures to predict severity
- Predictors of emergency department visits
- Predictors of hospital readmission
- Racial disparities
- Rehabilitation
- Re-hospitalizations/readmissions
- Work disability

Populations and topics screened out included

- Adolescents
- Children
- Drug treatments
- Drug trial outcomes
- Elderly
- Hospitalizations due to childbirth
- Hospitalizations for influenza, pneumonia, virus infections, *C. difficile*
- Infants
- Not American
- Patient perceptions of facilities, treatment, doctors/nurses
- Prenatal hospitalizations

- Safety and efficacy of surgery, surgical procedures
- Studies from foreign countries
- Surgical procedure comparisons
- Surgical procedures
- Treatment (surgical, drug) comparisons

The screened-in papers were categorized into health-care utilizations by body system and types of factors affecting health-care use. The committee members then examined abstracts in their areas of expertise. Their subsequent screening resulted in a final count of 575 articles. The most common categories of health-care utilization found in this body of literature were cardiovascular, mental health, neurologic, and respiratory.

After reading the full text of the 575 articles retrieved from the search, the committee members developed an additional search strategy to capture articles they believed might have been missing from the original search. The new topics and key words included

- Additional concepts of impairment severity: "Injury Severity Score OR Trauma Severity Indices OR Severity of Illness Index OR Abbreviated Injury Scale OR Simplified Acute Physiology Score OR Patient Acuity OR Risk Adjustment OR APACHE OR Neoplasm Grading OR severity[tiab] OR mortality"
- Ability to work: "Employment OR work[MAJR] OR unemployment OR public assistance OR work[ti]"
- Musculoskeletal injuries: "Wounds and Injuries"[Mesh]
- Medications, devices, and telehealth: "Prescription Drugs"[Mesh], ("Durable Medical Equipment"[Mesh] OR "Infusion Pumps"[Mesh] OR "Radiation Equipment and Supplies"[Mesh] OR "Airway Management"[Mesh] OR "Catheterization"[Mesh] OR "Renal Dialysis"[Mesh]), "Telemedicine"[Mesh]

Those additional searches were performed in June 2017, applying the same filters as the original search, resulting in 24,309 unique hits after deduplication with the original search. From those 24,309 titles, staff identified 445 that were potentially useful to the statement of task. The committee then carefully reviewed those abstracts and kept 133 articles.

In sum, the committee screened in 708 articles out of 60,915 found in the two searches. Those 708 articles were carefully reviewed to determine whether they could be used to inform an association between health-care utilizations and impairment severity. The selected papers (a total of 80) are discussed in Chapter 4 and Appendix C.

LITERATURE SEARCH STRATEGY: BACKGROUND READING AND HEALTH-CARE DELIVERY SYSTEM

In addition to PubMed, the following government and nongovernment research organizations' websites were searched for background materials on disability, health-care utilization, and changes in the health-care delivery landscape relevant to the task order objective:

- Agency for Healthcare Research and Quality (AHRQ)
- American Medical Association (AMA)
- Cochrane Reviews
- Congressional Research Service (CRS)
- Dartmouth Atlas of Healthcare

- Government Accountability Office (GAO)
- *Health Affairs*
- *Journal of Occupational and Environmental Medicine*
- Kaiser Family Foundation (KFF)
- Lexis Law Reviews
- Mathematica Policy Research
- National Academies of Sciences, Engineering, and Medicine (the National Academies)
- National Center for Health Statistics (CDC-NCHS)
- RAND Corporation
- Social Security Bulletin
- US Congressional Budget Office (CBO)
- US Social Security Administration (SSA)
- World Health Organization (WHO)

Staff searched these websites using the following terms:

- "Health care utilization"
- "Disability" OR "Disabled Persons"
- "Patient Protection and Affordable Care Act"
- "Delivery of Health Care"
- "Medical homes"
- "Patient-Centered Care"
- "Bundled payments"
- "Health services"
- "Social security"

C

Literature Review—Report Summaries by Body System

This appendix provides detailed descriptions of the reports summarized in Chapter 4, which were identified from the evidence review strategy outlined in Appendix B. Of the 60,000 papers identified in the search, the committee chose papers that most appropriately linked health-care utilizations to impairment severity, disability, and disease severity. The Social Security Administration (SSA) defines severe impairment and disability similarly, the difference being the extent of a person's inability to perform tasks over some period, that is, to perform any gainful activity in the case of severe impairment as opposed to performing substantial gainful activity in the case of disability (SSA, 2017).[1] Other organizations define disability differently. Disease severity refers to the presence and extent of disease in the human body, which can be evaluated through diagnostic testing and physiologic examination (Finlayson et al., 2004). Although the statement of task specifies that the committee should focus on impairment severity and SSA's definition of disability, the literature focuses on measures of disease severity. Thus, most of the papers included in this appendix link health-care utilizations with disease severity.

The committee focused on summarizing papers that were based on nationwide data, large samples, and study populations of working-age adults in the United States, but for body systems on which there was a paucity of literature, the committee also described papers that did not fit those criteria, such as ones that looked at mortality as an end point, ones that used study populations outside the United States, and ones that had a mean population age over 65 years. Because this was not a systematic review, papers were not graded, but each included study is described in detail. The number of studies included for each body-system summary is not proportional to the number of studies that the committee found in its literature search for each body system. Rather, the committee included papers it believed would be helpful in addressing the statement of task.

Definitions of severe impairment and disability varied in the literature reviewed by the committee. The committee's summaries used the terms as they were reported in the original articles.

---

[1] See CFR § 404.1505 for the full definition of disability.

MUSCULOSKELETAL SYSTEM

The committee initially identified 197 abstracts of potential interest and retrieved 77 full-text articles for review. It searched for a variety of musculoskeletal disorders and injuries, but most of the literature that the committee found was related to fractures. The six studies most relevant to the committee's task are described below.

In a retrospective cross-sectional study, Menendez and Ring (2015) analyzed the Nationwide Emergency Department Sample (NEDS) database, developed for the Healthcare Cost and Utilization Project (HCUP), of 285,661 people admitted to emergency departments (EDs) for proximal humerus fracture in 2010 and 2011 to identify predictors of hospital admission compared with direct discharges to home. Multivariate logistic-regression modeling showed that although hospital admission was associated with such measures of clinical severity as the presence of polytrauma or open fracture and a higher Charlson comorbidity index, many other, nonclinical factors were also predictive, such as Medicare and Medicaid insurance, metropolitan facilities, and residence in the Northeast even of people who had less severe injuries.

Young et al. (2009) conducted a retrospective database review of 4,889 workers' compensation (WC) cases with bone fracture in nine states to examine interactions between health-care utilization, work disability, rurality, and duration of work. Two measures of severity were used: multiple versus single body-part injury and closed versus open fracture. Work disability duration was measured by the total number of full days individuals were paid for time off work due to injury. After adjusting for age, sex, state, body part injured, industry, and occupation, Young et al. found that the relationship between health-care utilization and duration of disability or injury severity was influenced by whether the person lived in a rural or urban area. In particular, rural residents have shorter periods of work disability than urban residents when health-care utilization is low; urban residents have shorter disability when health-care utilization is high. Thus, health-care utilization does not predict work disability across the board; other factors affect health-care utilization to render it an insufficient proxy for disability or duration of disability in people who are receiving WC.

Young and colleagues (2015) reviewed a subset of the previously mentioned dataset to look at the relationship between the use of physical medicine and rehabilitation (PM&R) service and work disability score as well as differences between urban and rural residents. The subset included 2,216 people who had bone fracture, received physical therapy, and took at least 7 days off work. The study differentiated urban versus rural patterns of PM&R utilization based on four factors: number of services per week prior to returning to work (rural residents averaged fewer services), whether the patient used two or more passive PM&R services per week in weeks 1 to 8 of disability (less common for rural residents), the mean number of active PM&R services received in weeks 5 to 8 (higher for rural residents), and whether the patient received three weekly passive PM&R services in weeks 5 to 8 (more common for rural residents). After adjusting for such individual and injury characteristics as age, sex, state, site of injury, and occupation, they found that those who used health-care services in a rural setting returned to work faster than those who used services in an urban pattern. Longer disability duration was associated with long episodes of care, failure to transition to self-management, and passive services. Their work focused on methods of reducing health-care costs and, like their previous study, focused on WC cases.

A prospective study by Nemunaitis and colleagues (2016) considered predictors of functional outcomes after trauma. Although they focused on functional outcomes, their study of 879 mostly white male trauma survivors at a level 1 trauma center looked at injury-severity scores (ISSs) and Glasgow Coma Scale (GCS) scores of patients admitted to the ED. They found that older people and those who had government insurance were more likely to have poor discharge functional independence measure (FIM) scores than those who had commercial insurance, and that those who had lower ISS had higher discharge FIM scores. The study focused on functional outcomes, and one could surmise that those who had lower ISS and higher FIM scores used fewer health-care services; but the study did not address health-care utilizations, and any such conclusion would be a projection of the data presented.

Lipscomb et al. (2015) designed a retrospective cross-sectional study of whether declines in WC rates represent true improvement in health or a shift of care to other payment systems. The study excluded people who had multiple work-related injuries. In a sample of 18,768 mostly male carpenters in Washington State, private health-care utilization increased as WC claims declined. The report does not discuss long-term disability or return to work.

A retrospective chart review of a level 1 trauma center at Grady Memorial Hospital in Atlanta, Georgia, examined reasons for increased length of stay of patients 18–55 years old (mean age, 27 years) who were admitted for femoral-shaft fractures (Pendleton et al., 2007). Analyses were adjusted for demographics, including age and sex. The authors found that greater length of stay could be due to social reasons, such as homelessness; medical reasons, such as continued bleeding from surgical wounds, anemia that prevents progression with physical therapy, or infection; or hospital delays, such as time to surgery, time to be admitted to a rehabilitation facility, or radiology delays.

SPECIAL SENSES AND SPEECH

The committee searched for studies that relate health-care utilization with impairment severity for disorders of special senses and speech. It found three abstracts and retrieved all three for full-text review. No studies on health-care utilizations as indicators of impairment severity were identified. One study on ED visits by deaf patients is presented to provide evidence on types of utilization that are more or less probable for particular medical conditions.

A retrospective cohort study in an outpatient center in Rochester, New York, compared 200 randomly selected deaf users of American Sign Language (ASL) with 200 randomly selected hearing English speakers (McKee et al., 2015). The authors compared ED use between deaf and nondeaf patients. The random samples were not matched on demographics or comorbidities. After adjusting for age, sex, race, smoking history, and Medicaid status, McKee et al. found that the deaf ASL users were 97 percent more likely than the hearing controls to have utilized an ED in the preceding 36 months. The study did not review which factors led to increased ED utilization by deaf people. The study results suggest that deafness could be a comorbid condition that increases the likelihood of ED visits.

RESPIRATORY DISORDERS

The committee's literature search yielded 139 abstracts; the committee read 62 full-text papers and found 8 of them to be useful. Most of the studies focused on chronic obstructive pulmonary disease (COPD), and one focused on asthma.

Alcazar et al. (2012) identified factors associated with hospital admission for COPD, including respiratory symptoms, pulmonary function tests, anxiety and depression, and quality of life. In a multicenter, cross-sectional study of 127 patients (mostly males) whose mean age was 67 years, the authors analyzed numerous factors associated with hospital admission by using a logistic regression model. They found that a significantly greater percentage of those hospitalized than of those not hospitalized received mucolytics, oxygen therapy, and home mechanical ventilation. Significantly more hospitalized patients than nonhospitalized patients had a dyspnea grade of 3 or 4. Lung function was also lower in patients who had been hospitalized when measured in milliliters of forced expiratory volume in one second (FEV1). The researchers found differences in forced vital capacity, which was significantly lower in patients who required hospitalization. As measured by the EQ-5D index, a standardized instrument for measuring generic health status, quality of life was significantly lower in the hospitalized than in the nonhospitalized patients. Anxiety and depression tended to be lower among hospitalized patients, but differences were not statistically significant. The BODE index (a capacity index for COPD that stands for *b*ody-mass index, airflow *o*bstruction, *d*yspnea, and *e*xercise) and SpO_2 (partial oxygen saturation) were significantly lower in those hospitalized for COPD exacerbation and indicated greater severity of illness than those not hospitalized for COPD exacerbation. This study directly associates COPD hospital admissions with various measures of severity and quality of life.

Ekberg-Aronsson et al. (2008) sought to determine whether GOLD[2] stages (another measure of COPD severity) are associated with hospital admission rate. Higher GOLD stages indicate more severe COPD indicated by lower FEV1. On the basis of data from the Swedish Malmo Preventive Programme (MPP), the researchers studied 22,044 middle-aged people who participated in health screening in 1974–1992 and obtained hospital admission data on them until 2002. The researchers analyzed the association between hospital admission rate and GOLD stages, adjusting for age. The authors found that among smokers, hospital admission rates due to all causes were associated with higher GOLD stage. The results of the study provide further evidence that COPD hospitalization is associated with measures of disease severity, although the study involved a non-US population, and access to and threshold to admit in European hospitals are different from the US.

Fan et al. (2007) identified factors that predict COPD exacerbations, defined as hospitalization or ED visit for COPD. The researchers used data from the National Emphysema Treatment Trial (NETT), a randomized controlled trial of two methods of treatment for emphysema conducted in 1998–2002. They linked NETT clinical-trial data with utilization data from Medicare claims. The study population consisted of 610 patients with an average age of 66.5 years. COPD exacerbation was defined as a COPD-related ED visit or hospitalization with a primary discharge diagnosis code of *ICD-9* (*International Classification of Diseases, Ninth Edition*) 491, 492, 493, or 496. Multivariate logistic regression was used to predict the outcome

---

[2]GOLD stands for the Global Initiative for Chronic Obstructive Lung Disease. GOLD was launched in 1997 in collaboration with the National Heart, Lung, and Blood Institute (NHLBI is part of the National Institutes of Health) and the World Health Organization.

of COPD hospitalization or ED visit during the 1-year followup period. They found that BODE score, a measure of disease severity, predicted 1-year hospitalizations and ED visits for COPD. As for functional measures, dyspnea measured with a shortness-of-breath questionnaire was the most predictive of exacerbations. The study used a large, well-characterized sample, but the average age was higher than SSA's population of interest. Given those qualifications, the study showed that hospitalizations and ED visits for COPD exacerbations are associated with illness severity and measures of lung function.

Mullerova et al. (2015) studied outcomes and risk factors associated with hospitalizations for COPD exacerbation. The authors used data on 2,138 patients, with a mean age of 63 years, from the Evaluation of COPD Longitudinally to Identify Predictive Surrogate Endpoints (ECLIPSE) study, a 3-year longitudinal observational study conducted at 46 centers in 12 countries to characterize disease progression in COPD (Vestbo et al., 2008). They investigated factors associated with hospitalization for COPD exacerbations by using Cox proportional hazards and adjusting for a wide array of demographic and clinical variables. They also studied the association between time to first hospitalization for exacerbation during the study period and hospitalization for exacerbation before study entry. Mullerova et al. (2015) found that the factor most predictive of a hospitalization for exacerbation was a prior history of hospitalization for exacerbations (hazard ratio 2.71, p <0.001). Other factors that predicted hospitalization for exacerbations included severity of airflow limitation, poor health status, radiologic evidence of emphysema, and systemic inflammation.

Akazawa et al. (2008) conducted a retrospective case-control study design of trends in utilization for COPD patients compared with control. The authors examined medical and pharmacy claims data on more than 30 million people in the United States. The authors used data from United Healthcare, a large managed care plan in the United States. All plans in the analysis provide full insurance coverage for physician, hospital, and prescription drug services. COPD patients 40 years old and older were matched with three random controls by age, sex, region, and index date. COPD cohort members were identified on the basis of billing claims that had primary diagnoses that indicated COPD (*ICD-9* code 491.xx, 492.xx, 496.xx) or pharmaceutical claims for fluticasone propionate–salmeterol combination, salmeterol, ipratropium, or tiotropium. Trends in utilization 36 months before diagnosis were compared by using multivariate regression models between COPD patients and controls. COPD patients used 1.6 times more inpatient and ED services and 1.5 times more office visits than controls, after adjustment for age, sex, region, and most common comorbid conditions. COPD patients' health-care utilization experienced a marked increase in the month before diagnosis.

Quintana et al. (2015) identified predictors of length of stay of patients who had COPD exacerbations. They conducted a prospective cohort study of 1,453 patients who visited 16 EDs and were admitted to the hospital. The authors performed multivariate multilevel linear and logistic regression to find predictors of length of stay of COPD patients. The authors found that the best predictors of length of stay of COPD patients were baseline dyspnea, physical activity levels, and fatigue at 24 hours since admission; intensive care unit or intensive respiratory care unit admission; the need for antibiotics; and complications during hospitalization.

Sharif et al. (2014) studied readmission for COPD. The objective of their study was to determine predictors of readmission within 30 days of patients 40–64 years old who were hospitalized for COPD. They performed logistic regression of a retrospective cohort study by using a large national commercial database (N = 8,263). They found that early readmission was associated with patient factors, provider factors, and systems factors. Patient factors included

history of heart failure, lung cancer, osteoporosis, and depression. Provider factors included absence of prescription of statins within 12 months of hospitalization and absence of prescription of short-acting bronchodilators. System factors included length of stay and lack of postdischarge followup. The study described what affects intervals between hospitalizations for COPD patients and showed the complexity of predicting readmission for COPD.

Bai et al. (2007) investigated whether hospitalizations for worsening asthma or serious and reversible reduction in FEV1 are associated with a decline in lung function. A prospective European cohort of 281 adults who had predominantly moderate persistent asthma was initially evaluated in 1962–1975 and then re-evaluated in 1990 for measures of lung function. Measures of lung function included bronchial responsiveness, serum immunoglobulin E, and detailed lung-function tests. Participants were divided into two groups as having "frequent" and "infrequent" exacerbations, depending on how they compared with the median. The researchers analyzed the effect of hospitalizations and severe exacerbations on the annual decline of FEV1 by using a linear mixed-effects model. They found that the average FEV1 decline was 16.9 mL/year greater in the "frequent" group than in the "infrequent" group ($p = 0.03$). The study demonstrates that frequent exacerbations in asthmatics, including exacerbations that involve hospitalization, might be associated with lung-function decline. (Note that it was based on a European population.)

CARDIOVASCULAR SYSTEM

The committee initially identified 261 abstracts of potential interest and retrieved 116 full articles for review. It found more literature on cardiovascular diseases (CVDs) than any other body system in its literature search. Some articles provided an overview of CVDs, but most focused on specific cardiovascular conditions. The committee reports on 23 studies that focused on overall CVDs, heart failure (HF), ischemic heart disease (IHD), arrhythmias, and valvular disease as examples of studies that investigated disability associated with these disorders. For clarity, the 23 studies summarized in this section are grouped according to those categories.

General Cardiovascular Disease

A large prospective observational population-based study of Florida Medicaid patients compared a group of 15,775 patients who participated in a disease management intervention with 32,034 patients who received usual care (Afifi et al., 2007). All patients had at least one of the following chronic conditions: diabetes mellitus, congestive heart failure (CHF), hypertension, and asthma. The intervention consisted of telephone counseling by a trained managed-care specialist in 2001–2004. In models adjusted for demographics, severity of disease, comorbidities, and previous utilization, significantly lower rates of annual hospitalizations (ranging from 0.07 to 0.38 stays), lower lengths of stay (0.4 to 2.54 days), and fewer ED visits (0.10 to 0.91 visits) were reported in the disease management group. The study emphasizes the role that good patient counseling—even by telephone—can have in reducing expensive inpatient and emergency care. It also supports the idea that less expensive out-of-hospital followup might have a favorable effect on outcomes and that variation among patients and health-care systems might have to be considered in assessing inpatient utilization as a proxy for functionality.

Using data from the Baltimore Study of Black Aging, Thorpe et al. (2016) investigated self-reported activities of daily life in 602 black Americans who had chronic conditions, including CVD and diabetes. In models adjusted for age, education, income, and marital status,

men who had CVD had almost 3 times as high a risk of disability as men who did not report CVD. Inasmuch as people who had arthritis, depression, or diabetes were also found to have increased disability, the study documented the role of chronic conditions in functionality and suggested that multiple chronic comorbidities must be addressed when disability is evaluated.

Fan et al. (2009) studied the role of psychologic distress associated with disability in adults who had cardiovascular conditions. Data from the 2007 Behavioral Risk Factor Surveillance System, which collects data through random digit dial telephone surveys, on 177,663 respondents who were 35 years and older were used to evaluate disability on the basis of self-reports of activity limitations and use of special equipment. Overall, 12.5 percent had a history of CVD, and 9.2 percent had severe psychologic distress. People who had a history of CVD had a higher prevalence of psychologic distress than those who did not. Moreover, disability status was significantly greater in those who had psychologic distress than in those who did not, regardless of the rate of rehabilitation services received. No differences related to sex or employment status were found in levels of psychologic distress in those who had CVD after adjustment for other sociodemographic factors. The data confirm that psychologic factors must be considered to affect disability in people who have CVD.

Heart Failure and Cardiomyopathy

A 2013 systematic review evaluated the effects of social factors on hospital readmissions or mortality in which HF was an initial diagnosis (Calvillo-King et al., 2013). Some 52 studies published in 1980–2012 met criteria for inclusion. Greater age was associated with worse HF outcomes, but results by sex were inconclusive. Race influenced outcomes, with nonwhites having more readmissions but lower mortality. In studies that evaluated social factors, low socioeconomic status (SES, generally defined by income or Medicaid status), rural residence, home instability, lack of social support, being unmarried, and such medical factors as smoking, drug use, and medical visit nonadherence significantly increased the risk of readmissions. Those factors and psychiatric comorbidities, lack of home resources, and greater distance to a hospital were associated with increased mortality from HF. This systematic review emphasizes the need to consider a broad array of demographic and social factors as influences on hospital readmissions for HF.

Acknowledging that early readmission or death might indicate poor management for HF, Foraker and colleagues (2011) assessed the association of neighborhood median household income and Medicaid status with HF hospital readmissions of 1,342 participants in the Atherosclerosis Risk in Communities (ARIC) study followed over 17 years. They adjusted for covariates—race and study community, sex, age at incident HF hospitalization, and selected socioeconomic, clinical, and behavioral characteristics—and found that within 1 year 19 percent of patients had died, 59 percent had been readmitted, and 62 percent had been readmitted or died. Incident HF hospitalizations were more common among ARIC cohort participants who lived in low- and medium-neighborhood income areas than among those who lived in high-neighborhood income areas at baseline. Low-neighborhood income participants who had a high comorbidity index score at the time of the incident HF hospitalization were readmitted at a higher rate than high-neighborhood income participants in the same comorbidity category. Medicaid recipients who did not have a high burden of comorbidity tended to have a higher risk of first readmission and were readmitted more often than participants who were not receiving Medicaid. The study concluded that comorbidity burden appears to modify the association of neighborhood factors, Medicaid status, readmission, and death of HF patients.

Although quality of life is assumed to be intricately associated with functionality, few studies have attempted to investigate health-care utilization as a predictor. Acknowledging the value of information on frequency of hospitalizations, one study investigated inpatient stays as an approximation of patient functional status (Berchialla et al., 2010). A total of 235 patients participating in the Heart Muscle Disease Study Group who were treated in the Maggiore Hospital Department of Cardiology in Trieste, Italy, and had a diagnosis of dilated cardiomyopathy were followed over 15 years, from 1978–1992. Using a semi-Markov representation of the hospital process, the authors calculated that the probability of a second hospitalization within 1 year of the first is about 0.50 and within 2 years about 0.30. After the third hospitalization, the probability of not having another hospitalization within 1 year was 0.10. Use of beta blockers was a primary factor in increasing the interval between hospitalizations. The authors noted the importance of extracting as much detailed information as possible from hospital records. They emphasized that although the hospitalization process is only a rough approximation of patient status, it might be a reasonable approach with such diseases as dilated cardiomyopathies that have relatively fast worsening.

As noted previously, quality of life is often used to indicate patients' functionality in epidemiologic studies. A study of 1,458 patients who participate in the Efficacy of Vasopressin Antagonism in HF Outcome with Tolvaptan study (EVEREST) used the Kansas City Cardiomyopathy Questionnaire (KCCQ)[3] scores after discharge followed an HF admission to evaluate quality of life (Allen et al., 2011). Within 24 weeks of discharge, 478 (32.8 percent) patients had died and 192 (13.2 percent) had serial KCCQ scores under 45 (scores range from 0 to 100). After adjustment for 23 predischarge covariates, independent predictors of quality of life included a low admission KCCQ score, high brain type natriuretic peptide (BNP), hyponatremia, tachycardia, hypotension, absence of beta-blocker therapy, and history of diabetes mellitus and arrhythmia. Of interest is the role of BNP as a predictor of HF outcome, independently of other clinical factors and comorbidities. The authors noted that those predictors can be used to target aggressive treatment options for HF patients, but they also identify new measures that might be helpful in identifying patient functionality.

Only one study that specifically addressed functional limitations and readmission of HF patients was found (Yamada et al., 2012). In 215 patients who completed the Performance Measure for Activities of Daily Living-8 (PMADL-8) (higher scores indicating worse functionality) over a mean followup of 20 months, multivariate analyses resulted in only the PMADL-8 score associated with readmission for HF (hazard ratio [HR]: 2.49, 95% confidence interval [CI]: 1.27–4.90). Those in the highest functionality group had fewer events than others. Results indicate the prognostic value of self-reported physical function and its importance in predicting hospital readmissions.

In an approach similar to that above, Betihavas et al. (2015) developed a risk-prediction model for unplanned readmissions for HF. A prospective cohort of 280 patients in the Which Heart Failure Intervention Is Most Cost-Effective and Consumer Friendly in Reducing Hospital Care (WHICH?) trial, comparing home-based versus clinic-based interventions, was followed to document 18-month readmissions of participants. Factors associated with an increased risk of hospitalization for HF included age (HR: 1.07, 95% CI: 0.90–1.26) for each 10-year increase in age, living alone (HR: 1.09, 95% CI: 0.74–1.59), sedentary lifestyle (HR: 1.44, 95% CI: 0.92–

---

[3]The Kansas City Cardiomyopathy Questionnaire (KCCQ) is a well-established instrument used to evaluate the health status of heart failure (HF) patients (see Creber et al., 2012).

2.25), and the presence of multiple comorbid conditions (HR: 1.69, 95% CI: 0.38–7.58). This model confirms the importance of including comorbidities in assessing HF outcomes.

Because HF outcomes are usually reported in studies of older adults, the committee includes a study by Bibbins-Domingo et al. (2009), which addressed racial differences in incident HF in young adults. A cohort of 5,115 blacks and whites of both sexes who were 18–30 years old were followed for up to 20 years to identify the incidence and risk factors for HF. Only 27 participants developed HF, and all but one were black. Mean age at onset was 39 ± 6 years, which resulted in a cumulative incidence of HF before the age of 50 years of 1.1 percent (95% CI: 0.6–1.7). In blacks, risk factors for incident HF were higher diastolic blood pressure, higher body mass index, lower high-density lipoprotein cholesterol, and kidney disease. Myocardial infarction (MI), drug use, and alcohol use were not associated with the risk of HF. The study is an important contribution to the literature on working-age adults, identifying the race-related disparity in HF, but social factors were not addressed.

In contrast, a study tracked the natural history of HF matched white and nonwhite patients by using propensity scores (Gambassi et al., 2008). Of the 7,788 participants, who had chronic systolic and diastolic HF, enrolled in the Digitalis Investigation Group trial, 14.4 percent were nonwhite. Their propensity scores were used to match 1,018 pairs of white–nonwhite dyads on the basis of baseline characteristics, including 35 clinical measures of comorbidities and severity indexes. No measures of SES were included. Over a median of 38 months of followup, no racial differences were found in mortality (HR: 0.95, 95% CI: 0.80–1.14), all-causes hospitalization (HR: 1.03, 95% CI: 0.90–1.18), all-cause mortality (HR: 0.82, 95% CI: 0.6–1.11), or HF mortality (HR: 1.5, 95% CI: 0.91–1.22). The study found an increased risk of hospitalization for worsening HF among nonwhite HF patients. The authors concluded that racial difference in HF did not exist after controlling for a multitude of baseline factors, but the clinical measures reflected only baseline indicators of disease at the time of HF. Inasmuch as racial differences existed in baseline characteristics before matching, it is important to recognize that race might be a marker of other prognostic covariates.

A study of 78,801 patients from 257 hospitals participating in the AHA Get with the Guidelines-HF Program (2005–2008) evaluated HF outcomes and included 22.6 percent blacks and 6.0 percent Hispanics (Thomas et al., 2011). Clinical characteristics, adherence to guideline-based HF measures, and in-hospital mortality were addressed. Relative to white patients, Hispanic and black patients were younger (median age, 78.0, 63.0, and 64.0 years, respectively), had lower left ventricular ejection fractions, and were more likely to have diabetes mellitus and hypertension. Black and Hispanic patients had lower in-hospital mortality than white patients. In the context of a national HF quality-improvement program, HF care was equitable and improved in all racial and ethnic groups over time.

Ischemic Heart Disease

A large study evaluated national trends in MI hospitalization rates in patients under 65 years old by using the National Inpatient Sample (NIS) 1997–2006 (Towfighi et al., 2011). Temporal trends in sex-specific hospitalization rates were assessed in 2,824,615 US patients who were admitted with MI. The demographic and hospital characteristics for MI admissions in 1997 and 2006 were similar; in both years, most patients were white and male and had private insurance. Most MI admissions were to urban hospitals, and most patients were admitted through the ED. Among those who were 35–64 years old, men consistently had greater MI hospitalization rates than women. The temporal trends showed reductions in MI hospitalization

rates in both men and women, with a slightly greater reduction in men. The age-standardized rate decreased during the decade by 25 percent and 18 percent, from 168 to 126 and from 56 to 46 MI hospitalizations per 100,000 men and women, respectively. The absolute reduction in MI hospitalization rates was greater in men than in women. The most prominent decrease occurred in men 55–64 years old. The authors noted that the lower MI hospitalization rates in women than in men could be due partly to a failure to recognize and diagnose acute coronary syndromes in women. Sex should be taken into consideration inasmuch as severity of and prognosis in MI can vary between men and women in US hospitalizations.

A study of adverse events and later health-care utilization by patients who had a previous hospitalization for acute coronary syndrome (ACS) used data from a large commercial managed-care system in the United States (Korsnes et al., 2015). Patients were at least 18 years old at initial ACS hospitalization (the index episode) and had at least 12 months of continuous health-plan enrollment before and after the end of the index episode. Of 75,231 study patients identified, 3.3 percent had a serious adverse CVD event and 8.3 percent a second coronary event during the 12-month followup. Median time to first adverse and second coronary event from the end of the index episode was 4.6 and 3.7 months, respectively. Statin use and lower age were associated with lower episode-related costs. The study documented the relatively short time between initial hospitalization and recurrence for patients initially hospitalized with an ACS.

A study was undertaken to evaluate socioeconomic status (SES) on the basis of residential zip code in relation to prehospital clinical, access, and transport variables that might influence outcomes after acute MI (Agarwal et al., 2014). Using 372,984 discharges with a principal diagnosis of acute MI in the 2003–2011 NIS database, the study found significantly higher mortality in the lowest SES quartile than in the highest quartile (odds ratio [OR]: 1.11, 95% CI: 1.06–1.1). The mean adjusted cost of hospitalization was almost 4 times as high in patients in the highest SES quartile than in the lowest quartile. The authors concluded that disparities related to factors incorporated in SES must be considered when outcomes related to acute MI are evaluated.

Arrhythmia

An evaluation of health-care utilization associated with new-onset atrial fibrillation (AF) (less than 30 days after MI) and late-onset AF (at least 30 days after MI) was conducted among 1,512 patients enrolled in the Rochester Epidemiology Project (southeast Minnesota) with a mean followup of 3.9 years (Chamberlain et al., 2013). Hospitalizations and ED and outpatient visits at the Mayo Clinic in 2002–2010 were documented in the 237 patients who had prior AF, 163 who had new-onset AF, 113 who had late-onset AF, and 989 who did not have AF. Patients who had AF were older at the index MI and had a greater number of comorbidities; in particular, those who had AF before MI had worse renal function and were more likely to have prevalent HF and COPD than those who developed AF after MI or those who did not have AF. Rates of utilization differed in those who had AF from those who did not on the basis of timing of the arrhythmia. In fully adjusted models, those who had prior AF exhibited an increased risk of hospitalization (HR: 1.57, 95% CI: 1.29–1.91), those who had new-onset AF exhibited an increased risk (HR: 1.34, 95% CI: 1.11–1.63), and late-onset AF was associated with a greater increase in risk (HR: 2.18, 95% CI: 1.67–2.83) compared with people who did not have AF. A similar pattern was observed for both ED visits and outpatient visits, although with slightly smaller HRs. Absolute rates of utilization were not presented. The study provided evidence of AFs complicating MI and resulting in higher utilization associated with adverse outcomes and

poor prognosis. The combination of CVD outcomes and management of coexisting conditions should be considered in assessing disability.

The ARIC study also provided data on utilization associated with AF (Bengtson et al., 2014). Participants who had incident AF enrolled in fee-for-service Medicare for at least 12 continuous months during 1991–2009 (N = 932) were matched for age, sex, race, and field center with up to three participants who did not have AF (N = 2,729). During a mean followup of 4.1 years, there were 2,604 hospitalizations of the 932 AF participants; the median length of stay was 5 days (interquartile range: 3–9 days). There were 2,965 hospitalizations of the 2,729 AF participants during a mean followup of 4.2 years; the median length of stay was 5 days (interquartile range: 3–8 days). The unadjusted mean number of days of hospitalization per year was 13.2 (95% CI: 11.6–15.0) and 2.8 (95% CI: 2.5–3.1) for AF and non-AF participants, respectively. After adjustment for potential confounders, the rate of days in the hospital was 3.94 (95% CI: 3.29–4.73) times greater for AF participants. The unadjusted annual rate of outpatient utilization was 53.3 (95% CI: 50.5–56.3) and 22.9 (95% CI: 22.1–23.8) for AF and non-AF participants, respectively. Health-care utilization after AF diagnosis did not differ significantly by sex or race. Although the results did not provide correlations between utilization and functional status, they are useful in understanding both inpatient and outpatient utilizations by patients who had AF. The rates of utilization might have value in refinement of the SSA Listings. It should be noted that most participants in the ARIC study were over 65 years old.

Two studies reviewed rates of hospital readmission after inpatient admission for AF. Kim et al. (2009) conducted a retrospective cohort analysis by using data from the Healthcare Information Systems National Managed Care Benchmark Database (2002–2006) on 4,174 patients. Information on the first readmission within 1 year of the index hospitalization was analyzed. Overall, 12.5 percent of chronic AF patients were readmitted for AF with a mean time to readmission of 142.5 days (median, 108 days). Among newly diagnosed AF patients, 10.1 percent were readmitted for AF with a mean time to readmission of 133.8 days (median, 112 days). For chronic AF, 17.6 percent, 43.4 percent, and 65.8 percent of readmissions occurred within 1, 3, and 6 months, respectively, versus 22.7 percent, 44.5 percent, and 67.2 percent, respectively, for newly diagnosed AF. Opolski et al. (2015) investigated readmissions and repeat procedures after catheter ablation for atrial fibrillation or flutter (AF/AFL). These data were on 2,022 patients enrolled in the National Health Fund of Poland. After discharge for the index hospitalization, 123 (6.1 percent) and 540 (26.7 percent) patients were hospitalized because of AF/AFL within 30 days and 1 year, respectively. At 1-year followup, 192 (9.5 percent) patients underwent AF/AFL ablations. The patients that underwent the second ablation were younger than the ones who did not (56.6 ± 11.0 years versus 59.1 ± 10.8 years; p = 0.019) and the time of the index hospitalization was shorter (3.75 ± 2.16 days versus 4.45 ± 3.26 days; p = 0.03). Within 30 days and at the 1-year followup, 194 (9.6 percent) and 747 (36.9 percent) patients, respectively, were hospitalized. The data showed that more than one-fourth of patients who underwent AF/AFL ablation were hospitalized for arrhythmia recurrence in 1 year. Although information to associate the utilizations with disability was not sufficient, the study documents the high burden of inpatient care required for patients with AF.

Valvular Heart Disease

Using longitudinal data from the NIS, Badheka et al. (2015) describes trends in hospitalizations from 2000 to 2012 that resulted from aortic valve–related discharges in people 60 years old and older. The NIS, developed for the HCUP and sponsored by the Agency for

Healthcare Research and Quality (AHRQ), is the largest available database on hospital inpatient stays in the United States. Over the 12-year period, 113,847 hospitalizations with aortic valvular disease as the primary diagnosis (N = 561,880 for weighted national estimate) were reported in the United States in patients over 60 years old. The number of hospitalizations increased progressively from 7,213 in 2000 to 11,531 in 2012 (p <0.001). Hospitalized patients who had aortic valvular disease were predominantly non-Hispanic whites (69 percent) and over 70 years old (76 percent). Admissions of patients who had more comorbidities doubled from 25 percent in 2000 to 50 percent in 2012. The most frequent coexisting conditions in these patients were hypertension (58 percent), heart failure (35 percent), renal failure and anemia (26 percent each), diabetes (24 percent), and chronic pulmonary disease (18 percent). There were more admissions in the South (29 percent) than in any other region, followed by the Northeast (26 percent), the Midwest (22 percent), and the West (20 percent). Overall in-hospital mortality of patients hospitalized for aortic valvular (AV) disease significantly decreased from 4.5 percent in 2000 to 3.5 percent in 2012 (p <0.001). The total length of hospital stay has decreased from 8.4 to 7.8 days over this period (p <0.001); the cost of care during hospitalization increased significantly: from $1.28 billion in 2001 to $2.13 billion in 2011 (p <0.001) after adjustment for inflation. With the availability of more treatment options, an aging population, and the increasing cost of hospitalization, the burden associated with aortic valvular disease is of growing importance in the United States, but the effects on adults under 65 years old and return-to-work capacity are not known.

Only one study that evaluated outcomes in younger adults who had congenital valvular heart disease (VHD) (van der Linde et al., 2013) was found. A total of 414 patients (average 29 years, 68 percent male) were selected from prospective databases: the CONCOR database (the Dutch registry of adult patients who have chronic heart disease [CHD]) and the Leuven and Toronto database (of adults who have CHD). Patients were followed over a median duration of 4.1 (2.5–5.1) years. Chart abstraction was used to evaluate baseline and progression of aortic stenosis (AS). Increased left ventricular mass was significantly associated with faster AS progression (p <0.001). Aortic dilatation was present in 34 percent at baseline and 48 percent at followup (p <0.001). The rate of aortic dissection was 0.06 percent per patient-year. Some 70 patients required an aortic-valve intervention (4.4 percent per patient-year), with AS progression rate as the most powerful predictor (HR: 5.11, 95% CI: 3.47–7.53). The authors concluded that in young patients with mild to moderate congenital AS, the disease generally does not progress. However, people who have left ventricular hypertrophy are at risk for fast disease progression and should be monitored carefully. The results of the study might provide insights into VHD outcomes for working-age adults.

Many studies of VHD have focused on a specific (often new) procedure to compare outcomes of usual care. Severe AS, the most common acquired VHD, which has a poor prognosis once symptoms appear, is an example. In a review of 16 studies, Deutsch et al. (2013) investigated outcomes beyond survival, including functional status and health-related quality of life, and compared transcatheter aortic valve replacement (TAVR) with surgical aortic valve replacement. Reviewing metrics for assessing both physical components (such as physical function and body pain) and mental components (such as emotional health and social function) of health in 16 studies, the authors concluded that evidence is accumulating that TAVR in high-risk surgical patients who have severe symptomatic AS is associated with marked functional benefits, but most of these patients are elderly. Significant improvements in quality of life were detectable as early as 1 month after TAVR and were followed by clinical stabilization and were

detectable up to 1 year. The 1-year health status of the TAVR population has consistently been shown to become similar to age-matched general population norms. Whereas most studies involved older patients who had multiple comorbidities, disabilities, and short life expectancy, this review emphasized the value of using quality-of-life evaluation in assessing the outcome of therapeutic interventions in clinical practice.

Biomarkers also might prove valuable in objectively evaluating the health status of VHD patients after surgical procedures. Mizutani and colleagues (2017) sought to investigate the 2-year prognostic effect of BNP concentration at discharge after TAVR. In 1,094 patients followed during 2013–2016, the discriminating BNP concentration for discerning 2-year mortality was 202 pg/mL. High BNP was also found to have a statistically significant effect on other net outcomes, with an adjusted HR of 2.28 (1.36–3.82, p = 0.002). This study was conducted in older adults and needs to be duplicated in younger populations, but it suggests that incorporation of BNP stratification with other clinical variables might substantially improve predictive accuracy of outcomes of interventions for VHD.

DIGESTIVE SYSTEM

The committee initially identified 67 abstracts of potential interest and retrieved 24 full-text articles for review. The six studies most relevant to the committee's task are discussed below.

The committee identified one study that associated severity of a digestive condition with work productivity and resource utilization (Wahlqvist et al., 2008). It used data from the 2004 National Health and Wellness Survey, a self-administered, Internet-based questionnaire that captured health and behavior data on US adults. A total of 10,028 respondents who had gastroesophageal reflux disease (GERD) were matched to an equal number of age- and sex-matched controls. Symptom severity was self-assessed as mild, moderate, or severe. Work productivity was measured by using the Work Productivity and Activity Impairment questionnaire. Resource utilizations examined included physician visits, ED visits, hospitalizations, and GERD-related prescription-drug use. The authors found that as symptom severity increased, there was a significant increase in some health-care utilizations and a decrease in productivity by some measures. Specifically, for physician visits, there was a significant increase in health-care use from mild to both moderate and severe symptoms; for ED visits, there was a significant increase from mild to severe symptoms only; for hospitalizations, there was an increase for each level of severity that was not statistically significant; and for use of prescription proton pump inhibitors and histamine-2 receptor antagonists, there was a significant increase from mild to both moderate and severe symptoms. With respect to productivity, "hours absent from work per week" differed significantly between mild and severe symptoms. Although the study shows that increased severity is associated with an increase in some health-care utilizations by US patients who have GERD, the severity measure here is self-reported symptom severity rather than SSA's definition of impairment severity.

Another study focused on pain related to chronic pancreatitis. Mullady et al. (2011) studied whether patients who had chronic pancreatitis with various pain patterns experienced resource utilization, quality of life, and disability differently. This was a prospective cohort study in 20 US medical centers that consisted of 540 patients. The authors found that chronicity of pain, rather than severity of pain, was associated with greater rates of resource utilization and disability and lower quality of life. Patients in the cohort who had constant pain were more likely

to miss more than 5 days of work per month and more than three hospitalizations per year; however, it is unclear whether disability was associated with loss of productivity or other factors.

Dudekula et al. (2011) also focused on pain frequency, but for gastroparesis. The objective of their study was to determine predictors of hospital stays of patients who had gastroparesis. The authors conducted a retrospective chart review of 326 patients who were admitted to a hospital in Pittsburgh for gastroparesis in 2004–2008. They determined gastroparesis admission by using the *ICD-9* code 536.3 and found that more clinic visits took place in year 1 than in years 2–5 (p <0.01), whereas ED visits and hospitalization rates did not differ much over time. Nausea, vomiting, and abdominal pain were listed as primary concerns for greater than 70 percent of hospitalizations and ED visits. The length of hospital stay differed significantly based on the etiology of gastroparesis and the presence of psychiatric comorbidity. Factors that did not affect length of stay included chronic pain and opioid use. The report of the study provides some insight into trends in utilization for gastroparesis, although it does not specifically address impairment severity.

In a Swiss study of 1,187 patients followed up for an average of 13 months, Siebert et al. (2013) sought to identify predictors of work disability in patients who had inflammatory bowel disease (IBD). In Crohn's disease, such disease-related characteristics as fistulizing disease, duration of disease, number of relapses, and response to therapy were found to be associated with loss of work productivity and with disability.

Allegretti et al. (2015) studied risk factors for readmission within 90 days in patients who had IBD. They conducted a retrospective analysis of 356 patients at a hospital in Boston. IBD diagnosis was considered to include ulcerative colitis (*ICD-9* code 556.X) or Crohn's disease (555.X). They developed a Cox proportional-hazards model around two covariates of particular interest: depression and steroid use in the preceding 6 months. The final Cox model showed three variables that were risk factors for admission: depression (HR: 1.99, CI: 1.33–3.00), chronic pain (HR: 1.88, CI: 1.14–3.10), and steroid use in the last 6 months (HR: 1.33, CI: 0.92–2.04).

Myer et al. (2013) used the 2007 NEDS sample (N = 15 million) to identify leading causes of ED visits due to digestive diseases. They used logistic regression to analyze predictors of hospitalization after an ED visit. Leading primary diagnoses were abdominal pain, nausea and vomiting, and functional disorders of the digestive system. ED visits resulting in hospitalization were higher for primary digestive diagnoses versus nondigestive visits (21.6 percent versus 14.7 percent).

GENITOURINARY DISORDERS

The committee initially identified 67 abstracts of potential interest and retrieved 26 full-text articles for review. The four studies most relevant to the committee's task are discussed below.

One study provided evidence from national data that physician visits and hospitalizations can predict severity of chronic kidney disease (CKD) (Alexander et al., 2009), but it used a medical definition of severity rather than SSA's definition. There is also some evidence that worsening renal function (WRF) is associated with length of stay and readmission rate (Lanfear et al., 2011) and that some measures of utilization, when combined in a complex model, can predict WRF (Perkins et al., 2013).

Looking at National Health and Nutrition Examination Survey data on adult participants (N = 15,258), Alexander et al. (2009) studied the association between CKD and health-resource

utilization on the basis of self-reported physician visits and hospitalizations. They found that the mean number of annual physician visits increased significantly with CKD stage. That pattern was most evident in Mexican Americans, those under 65 years old, those who had Medicaid insurance, and those who had hemoglobin concentrations under 11 g/dL. Hospitalizations followed the same pattern. The pattern was most pronounced in Mexican Americans, younger adults, those who had body mass indexes (BMIs) less than 25, those who had hemoglobin concentrations less than 11 g/dL, diabetics, and those who did not report regular exercise.

Lanfear et al. (2011) conducted a retrospective analysis of 2,456 patients who had diagnoses of heart failure from 2000 to 2008 in a large health system in Michigan to look at long-term outcomes and readmission related to WRF. They found after adjustment that WRF, defined as a creatinine increase of at least 0.3 mg/dL, was associated with increased length of stay (7.0 days versus 3.8 days, p <0.001) and increased rates of readmission (p <0.001). Perkins et al. (2013) conducted a retrospective analysis to create a tool to predict 30-day readmissions for heart failure in people who had non-dialysis-dependent CKD. The final model included a number of variables, including resource utilization, comorbid conditions, medications, and laboratory results. Resource-utilization predictors included admission through the ED, admission as a transfer from another hospital, number of clinic visits in the 3 months before admission, discharge to a facility other than the home, and length of stay.

A study relating renal and cardiac disease looked at acute kidney injury (AKI) as a severity index for 30-day readmission after cardiac surgery (Brown et al., 2014). The authors collected data on 2,209 patients who underwent coronary artery bypass grafting (CABG) or valve surgery in seven hospitals in New England during 2008–2010. They evaluated the association between stages of AKI and 30-day readmission by using multivariate logistic regression. AKI stage 1 was defined as a 50 percent increase in serum creatinine concentration, stage 2 as a 100 percent increase, and stage 3 as a 200 percent increase if the baseline serum creatinine was at least 4.0 mg/dL or if it was a new dialysis. The results showed that those who did not develop AKI had a 9.3 percent 30-day readmission rate, those who had AKI stage 1 had a 16.1 percent readmission rate, those who had stage 2 had a 21.8 percent readmission rate, and those who had stage 3 had a 28.6 percent readmission rate (p <0.001). Thus, AKI stage could be a severity marker for 30-day readmission of patients who were undergoing CABG or valve surgery.

HEMATOLOGIC DISORDERS

The committee found 12 abstracts and retrieved all 12 for full-text review. The six studies most relevant to the committee's task are discussed below; all are related to sickle-cell disease (SCD).

Aisiku et al. (2009) collected diary data on ED utilization and pain descriptors and analyzed laboratory severity variables of 232 patients who had sickle-cell disease. People who have SCD are often stigmatized as opioid-seeking overutilizers of EDs. The authors found that about 35 percent were high users of the ED. High users had lower hematocrit levels, more transfusions, more pain days, more pain crises, higher mean pain and distress, and worse quality of life than other SCD patients on the basis of the Medical Outcome Study 36-Item Short Form Health Survey physical-function summary scales. After controlling for severity and frequency of pain, high ED utilizers were found not to use opioids more frequently than other SCD patients. The authors correlate ED utilization with several possible measures of disease severity.

In a trend analysis of SCD patients in Delaware, Anderson et al. (2014) examined hospitalizations, readmissions, and the cost of admissions for the study population. The study included adult residents who had SCD and received acute care in a small community hospital or a large community hospital system in 2007–2009. The authors ran descriptive statistics on age, length of stay, and hospital costs. There were 518 acute-care episodes during the period. They found that hospital costs and hospital readmissions within 7 and 30 days were rising while length of stay for acute care remained constant. The conclusions were that the cost of admissions for crises was high and that readmissions were common.

Brousseau et al. (2010) studied ED visits and hospital admissions for sickle-cell crises in a retrospective cohort study of more than 20,000 subjects over a 2-year period by using HCUP data from 2005–2006. Their primary outcome measures were hospital and ED utilization and readmission rate. They found frequent use of acute care encounters, defined as hospital and ED visits, by SCD patients. More than half the study population experienced acute care encounters during the study period. In total, the study population had more than 100,000 such encounters and averaged 2.59 encounters per patient per year, including 1.52 hospitalizations and 1.08 ED visits. Utilization was highest for people 18–30 years old. For those hospitalized, the 30-day readmission rate was 33.4 percent. The high 30-day readmission rate for sickle-cell crisis is a potential indicator of impairment severity, but the authors did not address this.

Leschke et al. (2012) performed a retrospective study of Wisconsin Medicaid claims data on adults and children in 2003–2007. Their primary outcome measures were readmission 14 and 30 days after a hospitalization for sickle-cell pain crisis. Of the 408 patients included in the study, 10 percent were readmitted within 14 days, and 17 percent within 30 days. The study also found that outpatient followup after hospitalization for sickle-cell crisis was associated with reduced readmission after both 14 and 30 days. The study did not directly discuss impairment severity; the high rate of readmission after sickle-cell admissions and the reduction in readmission in conjunction with outpatient followup are notable.

In a small study of 70 participants looking at health-care utilization and pain in people who had SCD, Sanders et al. (2010) compared utilization and pain variables between older (37–62 years old) and younger (18–36 years old) adult patients. The age distinction was based on survival data presented by Powars et al. (2005) that indicated a median survival time of sickle-cell patients of 36–39 years. The older group had more education; there was no significant difference in employment or marital status between the older and younger groups. The authors found that older sickle-cell patients were more likely to utilize outpatient facilities, whereas younger patients were more likely to use ED services. The two groups reported equivalent pain intensity, as measured by the Brief Symptom Inventory (Derogatis, 1993). The study indicates that health-care utilization by sickle-cell patients varies by age and cannot be generalized to all adults.

Wolfson et al. (2011) used statewide ED discharge data and found that 69 percent of sickle-cell patients in California utilized an ED each year, and they were most likely to use one facility. Over one-third were Medicaid patients. Adults were more likely than children to use multiple facilities and to be uninsured. In another study that used statewide data, the same group (Wolfson et al., 2012) found that adults had a higher frequency of utilization than children (possibly because of the coverage of children, which in California is superior to the overall coverage of adults). Distance from comprehensive SCD care and insurance status were significant predictors of ED utilization for SCD. Those who lived farther from facilities were more likely to use the ED but less likely to be hospitalized. The authors provided further

evidence that health-care utilizations by sickle-cell patients correlated with factors other than impairment severity.

SKIN DISORDERS

The committee identified four abstracts of potential interest and retrieved all four for full-text review. The two studies that are most relevant to the committee's task are discussed below.

Farrell et al. (2008) looked at the contribution of obesity to functional decline in patients who suffered from acute burns in a group of 221 mostly male patients whose average age was 43 years in a midwestern regional acute burn center. In the sample, 76 percent were discharged to home from the hospital, and the average length of stay was 16 days. The average total body surface area (TBSA) of the burns was 15 percent. The analysis found that in patients more than 57.5 years old who had less than 30.75 percent TBSA burns, BMI played a role in whether they were discharged directly to home versus to an inpatient setting. Of patients who had a BMI greater than 27.4, only 21 percent returned home; of patients who had a BMI of 27.4 or less, 65 percent returned home. The study also looked at FIM—ability to transfer to and from bed, ambulate, dress, and feed oneself. Functional independence was measured on a scale of 1–7 in which 1 indicated a requirement of total assistance and 7 indicating complete independence. The authors found that of patients who were 54.5–72.5 years old and had less than 22.5 percent TBSA burns, those who had a BMI greater than 25.15 had an average FIM score of 3.778, whereas those who had a BMI less than 25.15 had an average FIM score of 5.400. The study made a case that obesity is a comorbidity that can impair functional ability in this population of burn patients, as evidenced by discharge disposition and functional measures.

Kimball et al. (2014) studied the presence of malignancies and hospitalizations of a group of people who had psoriasis, a chronic inflammatory skin condition. In a national sample of more than 40,000 people, the authors calculated the standardized incidence of hospitalizations for severe psoriasis infections and total malignancy rates over a 36-month period. They examined outcomes of people who had psoriasis vis-à-vis their treatment modality. The authors found that people who had psoriasis were at greater risk for lymphoma regardless of treatment: 9 cases per 10,000 person-years compared with 6 cases per 10,000 person-years. There was little difference in the rates of lymphoma in people who had different treatments. The risk of hospitalization was highest in those who were exposed to tumor necrosis factor antagonistic therapies, not phototherapy or no treatment. Thus, psoriasis might be a comorbid condition that indicates increased risk of hospitalization for patients who have lymphoma.

ENDOCRINE DISORDERS

The committee initially identified 25 abstracts of potential interest and retrieved all 25 full-text articles for review. Four studies that looked at the effect of diabetes mellitus (DM) as a comorbid condition on disease severity and hospitalization are discussed below.

Jang et al. (2016) assessed hospitalized patients who survived an EMS-assessed out-of-hospital cardiac arrest in the ED in 2009–2013 (N = 2,651) and who received a diagnosis of DM to determine whether having DM affected survival to discharge and recovery of patients who had cardiac disease. They found that DM had a significant negative association with survival outcomes in those who had cardiac disease but no significant association in those who did not

have cardiac disease. The study provided evidence that survival of patients hospitalized for DM is related to cardiac disease.

Another study (Nadjiri et al., 2016) examined use of coronary computed tomographic angiography in diabetic patients and showed that patients who had a poorer performance on their imaging had a higher event rate when the end point was a composite of cardiac events defined as all-causes death, nonfatal myocardial infarction, or unstable angina requiring hospitalization. Diabetes as a comorbid condition might predict increased hospital and ED utilization for cardiac events.

Another study looked at the association between depression and hypoglycemic episodes that required ED visits or hospitalization (Katon et al., 2013). This longitudinal cohort study of 4,117 diabetic patients used major depression as the exposure of interest and the *ICD-9* code for a hypoglycemic episode that required an ED visit or hospitalization as the outcome of interest. The authors found depression to be significantly associated with time to first severe hypoglycemic episode. The study provided further evidence that comorbidities are important in associating health-care utilizations with disease severity in diabetes patients.

Regarding duration of utilization, one study looked at predictors of morbidity among patients after pancreatectomy (Jaap et al., 2016). A retrospective chart review from 2004 to 2013 (N = 180) found that the best predictor of length of stay and surgical complications was sarcopenia.

NEUROLOGIC DISORDERS

The committee initially identified 96 abstracts of potential interest and retrieved 67 full-text articles for review. The eight studies most relevant to the committee's task are discussed below.

Using data collected in 1998–2009 through the Medical Expenditure Panel Survey, Libby et al. (2012) compared health-care utilization by people with a diagnosis of epilepsy (N = 1,026, weighted to be nationally representative, N = 864,958) with health-care utilization by those who did not have epilepsy (N = 383,090). After covariate adjustment, people who had epilepsy had higher than expected rates of health-care provider visits and medication prescriptions. The relationship between health-care utilization and work-related disability was not evaluated, but those who had epilepsy were less likely to be employed and had more missed work days because of injury or illness. Wage-based lost productivity was greater than that observed in the combination of people who had depression, diabetes, anxiety, or asthma.

A retrospective study using the Medstat Marketscan Commercial Claims and Encounters database showed that people who had multiple sclerosis (MS) (N = 1,411) were 3.5 times as likely as matched healthy controls (N = 7,055)—excluding people who had comorbid conditions—to be hospitalized, 2 times as likely to visit the ED at least once, and 2 times as likely to receive one of the rehabilitation therapies (physical, occupational, or speech therapy) during the year after the first diagnosis or MS medication treatment (Asche et al., 2010). In addition, 30 percent were prescribed MS-specific medications, and, as a group, people who had MS were more likely than healthy controls to be prescribed antipsychotics, antidepressants, anticonvulsants, urinary antibiotics, and amphetamines.

Thomas and Ellis (2013) used data on North Carolina Medicaid recipients who received Supplemental Security Income (SSI) (N = 60,190) to examine whether health-care utilization predicted gainful employment, defined by eligibility code 1619b (earnings level indicating that a

person no longer needs cash payments). People who had any kind of disability were included in this analysis as long as they lived in the community and had received only outpatient services (no inpatient claims). People who had psychiatric or cognitive disability were found to use health-care services the most. More health-care service days were associated with less likelihood of employment, but the effect size was small. When diagnostic groups were examined relative to employment, those who had developmental disability and other neurologic disorders were among those who had the lowest odds of employment. The relationship between health-care utilization and employment was not evaluated relative to diagnosis.

Jones et al. (2016) utilized a national survey of neurologists and their MS patients (N = 715 patients) in 2013–2014 to evaluate the relationship between health-care utilization and disability. The neurologists used the Expanded Disability Status Scale (EDSS) to evaluate disability, in which a score over 5 indicates severity that can impair activities of daily living (ADLs) and impede working a full day. Some of the patients (N = 335) also answered questions about employment status, work productivity, and time lost at work because of MS. During the preceding 12 months, patients who had EDSS scores over 5 had more encounters with neurologists (incidence rate ratio [IRR] 1.4), nurses (IRR 44.4), physical therapists (IRR 9.9), and urologists (IRR 7.2). They also had more hospitalizations (IRR 3.3). The relationship between health-care utilization and work-related disability was not directly evaluated; however, when compared with patients who had no or minimal disability, patients who had EDSS scores over 5 were more likely to be unemployed (odds ratio [OR]: 12.4), more likely to have had problems in getting a job or promotion (OR: 17.0), or more likely to have had to stop working because of MS (OR: 10.4).

Health-care utilization by and outcomes of patients who have sustained traumatic brain injury (TBI) have also been examined. Collie and Prang (2013) examined trajectories of health-care utilization over 5 years in Australia by using compensation-claims data on 316 adults who had sustained severe TBI. They found four types of trajectories, two of which showed that health-care utilization remained at a relatively high level at the end of the 5 years. The people who had those trajectories showed greater and increasing use of attendant care to assist with disability. Attendant care is generally provided to assist with self-care, supervision, and health management, so it is unlikely that a person who has attendant care for TBI would be able to work. The study shows some link between health-care utilization and severity of TBI, but the relevance of the findings to work-related disability is even less direct than that found for MS.

Forslund et al. (2013) sought to identify predictors of employment 2 years after moderate to severe TBI (N = 100) and included receipt of rehabilitation services at 1 year among the factors evaluated. Those who were receiving rehabilitation services at 1 year were less likely to be employed at 2 years; this suggests that rehabilitation services are a marker of injury severity. In the multiple-regression analysis, rehabilitation services did not remain a significant predictor.

Zhang et al. (2015) analyzed public datasets from the 1995 National Institute of Neurological Disorders and Stroke tissue plasminogen activator study (N = 605) and found that discharge disposition at the completion of the acute hospitalization for stroke—home versus skilled nursing facility (SNF), rehabilitation, or death—was a strong predictor of disability at 3 months (modified Rankin score: ≥ 3), with an OR for acute rehabilitation versus home of 13.51 and an OR for SNF versus home of 28.50.

Bolge et al. (2010) examined health-care utilization and lost work productivity among those who reported chronic sleep maintenance insomnia characterized by nighttime awakenings (CINA) in the 2006 US National Health and Wellness Survey. Those who had CINA had

significantly greater health-care utilizationh than those who did not, were less likely to be working full time, and, if working, had more absenteeism and presenteeism. The relationship between health-care utilization and work productivity was not directly examined.

MENTAL DISORDERS

The committee initially identified 125 abstracts of potential interest and retrieved 53 full-text articles for review. The two studies that linked health-care utilization with impairment severity associated with mental disorders are discussed below. The majority of the papers identified for mental disorders pertain to mental disorders as a comorbid condition—those 20 papers are discussed more generally in Chapter 4.

Naz et al. (2007) followed a cohort of 87 respondents in New York who were 15–60 years old and had a major depressive disorder with psychotic features over a period of 4 years. They found that poorer utilization of prehospital resources predicted remission but not relapse, whereas medication use was not associated with remission or relapse. In this multivariate analysis, other factors were found to be associated with longer time to remission, including longer intervals between initial episode and hospitalization, lack of insurance, and lower prehospital Global Assessment of Functioning Scale scores.

A study of first-episode schizophrenia patients who participated in a randomized trial of enhanced psychosocial interventions provides direct information about the lack of association of pre-award utilizations and the eventual award of disability compensation (Rosenheck et al., 2017). In the Recovery After an Initial Schizophrenia Episode–Early Treatment Program study, first-episode psychosis patients were randomized to receive treatment as usual (TAU) or an enhanced psychosocial intervention. Over the course of the 2-year period of the study, 34 percent of the participants were awarded Social Security disability benefits. There were no differences between the enhanced intervention and TAU in the proportion of cases awarded benefits, although the enhanced intervention led to improvements in quality of life and symptoms. Predictors of receiving a disability award during the treatment period were less education, being unemployed or not going to school, less likelihood of private health insurance, longer duration of untreated psychosis, greater age, more clinician-rated disability, and higher positive symptom ratings on the Postive and Negative Syndrome Scale. Thus, more severe illness predicted disability compensation, and the intervention, although successful in some ways, did not change the trend toward compensation.

CANCER

The focus of the literature search for cancer is not on a particular body system but rather on diagnoses that might affect many organs or systems, although many articles tend to address a single site. The committee identified 99 abstracts and reviewed 28 articles thoroughly. The 14 that provide information of potential value to the committee's task are discussed below.

Rahman and colleagues (2015) followed 196 consecutive patients at the Dana-Farber/Brigham and Women's Cancer Center who had newly diagnosed glioblastoma to estimate their risk of hospitalization after treatment. Median overall survival of patients was 15.6 months. Some 46 percent were hospitalized during the chemoradiation phase of their treatment because of generalized weakness (17 percent), seizures (16 percent), or venous thromboembolism (13

percent). Hospitalization during chemoradiation was associated with a 47 percent increase in mortality. The data provided here demonstrate that morbidity associated with treatment for a cancer diagnosis is often the source of inpatient admissions.

To understand rates of readmission after surgery for gastric cancer, Merchant et al. (2015) followed 8,887 patients for 90 days after curative-intent surgery. Of them, 29 percent were readmitted to the hospital as inpatients at followup, most of them in the first 30 days after discharge, and almost 14 percent of the 29 percent had more than one readmission (range, 2 to 10 readmissions). After adjustment for other factors, readmission was associated with worse 5-year overall survival with an increased risk of death of 40 percent (HR: 1.4; 95% CI: 132–149). Readmission was increased by 15 percent in patients who had one comorbidity and 45 percent in those who had two or more. Although these results document the high rate of hospital readmissions in patients after gastric surgery, the statistics do not provide numbers that are useful in helping to decide the number of readmissions that constitutes disability or inability to work.

Karhade (2016) investigated 30-day readmissions after surgery for primary and secondary spinal tumors in a study that used a national registry to evaluate incidence and predictors of readmissions, adverse events, and reoperations. Data on 2,207 patients from the National Surgical Quality Improvement Program registry were analyzed to identify predictors of study outcomes on the basis of demographics, tumor characteristics, preoperative functional status, comorbidities, laboratory measures, and hospital factors related to the surgery. Readmission occurred in 10.2 percent of patients a median of 18 days after surgery. The most common causes were surgical-site infections (23.7 percent), systemic infections (17.8 percent), venous thromboembolism (VTE, 12.8 percent), and central nervous system complications (11.9 percent). Predictors of readmission included comorbidities (dyspnea, hypertension, and anemia), disseminated cancer, prior steroid use, and extended surgical hospitalization. Major complications occurred in 14.4 percent of patients: primarily VTEs, surgical-site infections, and sepsis, which were related to dependent functional status, emergency status, male sex, and comorbidities. The 30-day mortality was 3.3 percent. Those results highlight the role of comorbidities in postoperative sequelae of cancer surgery and the need to consider increased surveillance after hospital discharge.

Several papers from the same study team (Braithwaite, 2010; Izano, 2013, 2014) described functional limitations of women who had breast cancer. In a prospective cohort study of 2,202 women who had stage I, II, or III breast cancer diagnosed in 1997–2000 in the Kaiser Permanente Cancer Registry or the Utah Cancer Registry (Braithwaite, 2010), the long-term prognostic role of functional limitations was described, and complete information on body functions was collected, including endurance, strength, range of motion, and small-muscle dexterity after adjuvant treatment. During a followup of 9 years, 269 deaths (12.2 percent of the cohort) occurred, 7 percent from breast cancer and 5 percent from competing causes. Functional limitations were found in 39 percent of patients and were statistically associated with mortality, although the risk was greater for stage I than for stage III tumors. Women who had functional limitations tended to be older, less educated, and obese. The authors concluded that physical function in breast cancer patients was an important predictor of survival irrespective of clinical, lifestyle, and sociodemographic factors and should be addressed to improve longevity and quality of life of survivors. It is important to understand that disability often precedes death of cancer patients.

Two papers by Izano and colleagues described the effects of functional limitations and decline on mortality in black and white women. In a cohort of 975 women who had newly

diagnosed breast cancer in the Detroit-based Health and Functioning in Women Study (Izano et al., 2013), all-causes mortality increased significantly in women who had any functional limitation and specifically in those who had difficulties in pushing or pulling large objects, writing, handling small objects, or walking a half-mile. However, functional decline was associated with breast cancer mortality in regional or remote but not localized disease. Results did not differ by race, but the relationships were strongest in overweight and obese women. Data on 999 women taken from the same cohort who were followed for a median of 11 years (Izano et al., 2014) showed higher mortality in black women who had greater functional limitations and later-stage breast cancer. Comorbidities were associated with other-causes mortality and did not differ by race.

A study of 647 cancer survivors who were 55–65 years old and enrolled in the Penn State Cancer Survivor Study investigated the long-term effects of cancer and its treatment on employment and productivity to quantify disability that is attributable to cancer and to compare rates of disability in cancer survivors with rates in similarly aged people who have other conditions from the Health and Retirement Study (HRS) (Short et al., 2008). Work disability was measured as self-reported impairment or health problems that limited the kind or amount of paid work that subjects could do, a standardized metric strongly associated with employment status. Greater than 70 percent of cancer survivors had been employed at the time of their diagnosis, and about half reported that their disability was related to the cancer itself. The study found the rate of work disability in cancer-free survivors to be almost twice as high as in people who had no chronic conditions. Similar rates of disability, however, were found in cancer survivors and in those who had other chronic conditions, such as heart disease, stroke, diabetes, and lung disease; this highlights the chronic nature of effects even in successfully treated cancer patients. The authors concluded that cancer survivorship should be viewed as a chronic condition that requires a broad array of social services. The study is important in that it documented the effects of cancer on work disability, although it noted that, unlike other chronic conditions, disability is commonly caused by treatment that results in chronic pain and poor functional outcomes rather than by the disease itself.

Another study reported that cancer survivors under 65 years old were more than 3 times more likely to be unable to work because of a health condition than those who had no history of cancer or other chronic diseases (Hewitt et al., 2003). Using the National Health Interview Survey for 1998–2000, the authors compared 4,878 cancer survivors with 90,737 people who had no history of cancer to review general health status, psychologic disability, limitations in ADLs, physical function, and health-related inability to work. Those who had a history of cancer were more likely to have three or more chronic conditions and higher rates of psychologic problems, ADL difficulties, and functional limitations. Almost 17 percent reported being unable to work, and an additional 7 percent had health-related work limitations. Of those who had a history of cancer, 19.5 percent received SSI disability benefits. The authors also noted that cancer survivors who had comorbid chronic conditions had a much higher likelihood of disability than those without comorbid chronic conditions, although the odds of having the functional limitations described here remained higher than the odds in noncancer respondents even when they did not have other chronic conditions. Use of physician care was assessed and found to be similar to that by controls, but hospitalizations were not assessed. The authors noted that inasmuch as cancer is primarily a disease of the elderly, the aging of the US population will increase disabilities and the need for supportive services to address them. The study did not

identify health-care utilizations that would be useful in distinguishing cancer survivors' disabilities, but it did yield evidence that disabilities are likely to increase.

Another national population-based sample was used to estimate the burden of illness of cancer survivors compared with people who did not have a history of cancer (Yabroff et al., 2004). Multiple measures of disease burden—including utility (a summary measure of health status in multiple domains of health-related quality of life), lost productivity, and functional limitations—were all higher in 1,823 cancer survivors than in 5,469 age-, sex-, and education-matched controls. Cancer survivors were less likely to have held a job in the preceding month, more likely to have been unable to work because of health, more limited in the type of work that they could do, and had lost more days from work than controls. Of the cancer survivors, 18 percent had been unable to work in the preceding month, 27 percent were more limited in the kind of work that they could do, and had lost 50 days from work in the preceding year; productivity varied among cancer types. That length of time since diagnosis did not alter results reflects a poor prognosis for complete recovery. Health-care utilization was not reported in this study, but it confirmed the employment limitations that result from a cancer diagnosis.

Bradley and Bednarek (2002) took a different approach in analyzing data on cancer survivors at earlier stages who might be younger and more likely to return to work. Their goal was to investigate employment patterns of 253 long-term cancer survivors registered in the Detroit Surveillance, Epidemiology, and End Results Program (SEER) population. Patients were interviewed 5–7 years after their diagnosis of breast, prostate, colon, or lung cancer. Telephone surveys used questions on employment taken from two other studies, the health and retirement study and the Current Population Survey. The patients had a mean age of 62 years; data on demographics, employment status, hours worked, reasons for not working, absenteeism, job changes, and issues regarding retirement were collected. More than two-thirds of patients who had been working at the time of their diagnosis were employed 5–7 years later. Of patients who were no longer actively employed, 54 percent had retired, 24 percent had left their jobs because of poor health, and 9 percent were not working because their business had closed. The authors concluded that although it was clear that cancer had imposed some degree of limitation on some patients, especially in physically demanding jobs, the employment outlook for many patients will be promising as screening becomes more routine and working-age adults' conditions will be diagnosed earlier.

Other studies have focused on quality of life (QOL) as a patient outcome. Reduced mental and physical QOL was found to be significantly higher in patients who had several types of cancer (prostate, colorectal, and spinal), in particular demographic groups, and in people who had particular types of treatment (Sharma et al., 2007; Charlton et al., 2015; Choi et al., 2016; Farris et al., 2017). Those papers described risk factors for reduced QOL of cancer survivors, but direct associations with health-care utilization were not reported.

IMMUNE-SYSTEM DISORDERS

The committee initially identified 36 abstracts of potential interest and retrieved 33 full-text articles for review. The six studies most relevant to the committee's task are discussed below.

Two studies looked at ED visits of and disease severity in patients who had immune disorders. Panopalis et al. (2010) conducted a retrospective cohort study (N = 807) in San Francisco of patients who had systemic lupus erythematosus (SLE) to determine predictors of

frequent ED use. One factor examined was disease severity as determined by score on the Systemic Lupus Activity Questionnaire (SLAQ). Their data show that SLE patients who had more than three ED visits per year had higher disease severity than those who had one or two ED visits per year. SLE patients who had zero visits per year had the lowest disease severity. Another study examined ED utilization by human immunodeficiency virus (HIV) patients (Josephs et al., 2010). In this study, 951 patients were asked during in-person interviews to recall their ED visits in the preceding 6 months. The researchers then identified factors associated with the ED visits and admission to the hospital from the ED. They found that the likelihood of 6-month ED visits was 1.4 times higher among acquired immunodeficiency syndrome (AIDS) patients who had low CD4 (cluster of differentiation 4) counts ($< 50/mm^3$) than among patients who had normal CD4 counts. The likelihood of 6-month ED visits was 2.2 times higher among disabled than among nondisabled AIDS patients and 1.3 times higher in unemployed than in employed AIDS patients. Those findings suggest that frequency of ED utilization might reflect disease severity in patients who have immune diseases.

Two studies linked hospitalizations with disease severity as defined by clinical manifestations of AIDS, such as CD4 count. Kerr and colleagues (2012) conducted a retrospective analysis of 2,454 patients who were infected with AIDS. They found that HIV patients who had the clinical manifestations of AIDS for more than 1 year were more frequently hospitalized and spent more total days in the hospital than patients who had AIDS for less than 1 year, who in turn were more frequently hospitalized and spent more total days in the hospital than asymptomatic HIV patients. In a prospective cohort study of HIV-infected patients at 11 HIV care sites around the United States, Yehia et al. (2012) found that the annual rate of hospitalization was more than 5 times higher among AIDS patients who had low CD4 counts ($<50/mm^3$) than among AIDS patients who had normal CD4 counts. Similarly, the annual risk of hospitalization was nearly 2 times higher among AIDS patients who had a high viral load (>100,000 copies) than among those who had a normal viral load. Those studies provided evidence that greater clinical severity is associated with increased hospital utilization by HIV and AIDS patients.

Given that SLE is associated with one of the highest readmission rates among chronic diseases, Yazdany et al. (2014) examined hospital discharge data from five states—31,903 SLE patients, including 9,244 readmissions within 30 days of discharge—to identify predictors of readmission. One predictor found was that patients readmitted to the hospital within 30 days of discharge had significantly greater disease severity (as determined by the Ward Index) than those who were not. Thus, hospital readmission could be associated with disease severity in SLE patients.

One study identified by the committee linked outpatient-clinic utilization with disease severity. A cluster analysis of data on 1,748 HIV-infected patients at a large medical center found that those who had fewer than two clinic visits per year were less likely to have a favorable viral load and less likely to have a favorable CD4 count than those who had three or more visits per year (Palma et al., 2015). Those who had more than six visits per year were also less likely to have a favorable CD4 count. The study suggested that frequency of outpatient-clinic use might reflect disease severity in HIV patients.

The committee's literature search found one study that linked prescription medication utilization with disease severity in people who had immune disorders. Fielden and colleagues (2008) conducted a retrospective study of 1,605 HIV-infected patients who initiated highly active antiretroviral therapy (HAART) in 1996–2001. Their results showed that AIDS patients

who had less than 95 percent adherence to HAART were 1.88 times more likely to be hospitalized than those with higher rates of medication adherence. The study thus suggested a link between adherence to HAART and disease severity as measured by hospitalization of AIDS patients.

REFERENCES

Afifi, A. A., D. E. Morisky, G. F. Kominski, and J. B. Kotlerman. 2007. Impact of disease management on health care utilization: Evidence from the "Florida: A healthy state (FAHS)" Medicaid program. *Preventive Medicine* 44(6):547–553.

Agarwal, S., A. Garg, A. Parashar, W. A. Jaber, and V. Menon. 2014. Outcomes and resource utilization in ST elevation myocardial infarction in the United States: Evidence for socioeconomic disparities. *Journal of the American Heart Association* 3(6):e001057.

Aisiku, I. P., W. R. Smith, D. K. McClish, J. L. Levenson, L. T. Penberthy, S. D. Roseff, V. E. Bovbjerg, and J. D. Roberts. 2009. Comparisons of high versus low emergency department utilizers in sickle cell disease. *Annals of Emergency Medicine* 53(5):587–593.

Akazawa, M., R. Halpern, A. A. Riedel, R. H. Stanford, A. Dalal, and C. M. Blanchette. 2008. Economic burden prior to COPD diagnosis: A matched case-control study in the United States. *Respiratory Medicine* 102(12):1744–1752.

Alcazar, B., C. Garcia-Polo, A. Herrejon, L. A. Ruiz, J. de Miguel, J. A. Ros, P. Garcia-Sidro, G. T. Conde, J. L. Lopez-Campos, C. Martinez, J. Costan, M. Bonnin, S. Mayoralas, and M. Miravitlles. 2012. Factors associated with hospital admission for exacerbation of chronic obstructive pulmonary disease. *Archivos de Bronconeumologia* 48(3):70–76.

Alexander, M., B. D. Bradbury, R. Kewalramani, A. Barlev, S. A. Mohanty, and D. Globe. 2009. Chronic kidney disease and US healthcare resource utilization in a nationally representative sample. *American Journal of Nephrology* 29(5):473–482.

Allegretti, J. R., L. Borges, M. Lucci, M. Chang, B. Cao, E. Collins, B. Vogel, E. Arthur, D. Emmons, and J. R. Korzenik. 2015. Risk factors for rehospitalization within 90 days in patients with inflammatory bowel disease. *Inflammatory Bowel Diseases* 21(11):2583–2589.

Allen, L. A., M. Gheorghiade, K. J. Reid, S. M. Dunlay, P. S. Chan, P. J. Hauptman, F. Zannad, M. A. Konstam, and J. A. Spertus. 2011. Identifying patients hospitalized with heart failure at risk for unfavorable future quality of life. *Circulation: Cardiovascular Quality and Outcomes* 4(4):389–398.

Anderson, N., J. Bellot, O. Senu-Oke, and S. K. Ballas. 2014. Characteristics of acute care utilization of a Delaware adult sickle cell disease patient population. *Population Health Management* 17(1):60–65.

Asche, C. V., M. E. Singer, M. Jhaveri, H. Chung, and A. Miller. 2010. All-cause health care utilization and costs associated with newly diagnosed multiple sclerosis in the United States. *Journal of Managed Care & Specialty Pharmacy* 16(9):703–712.

Badheka, A. O., V. Singh, N. J. Patel, S. Arora, N. Patel, B. Thakkar, S. Jhamnani, S. Pant, A. Chothani, C. Macon, S. S. Panaich, J. Patel, S. Manvar, C. Savani, P. Bhatt, V. Panchal, N. Patel, A. Patel, D. Patel, S. Lahewala, A. Deshmukh, T. Mohamad, A. A. Mangi, M. Cleman, and J. K. Forrest. 2015. Trends of hospitalizations in the United States from 2000 to 2012 of patients >60 years with aortic valve disease. *American Journal of Cardiology* 116(1):132–141.

Bai, T. R., J. M. Vonk, D. S. Postma, and H. M. Boezen. 2007. Severe exacerbations predict excess lung function decline in asthma. *The European Respiratory Journal* 30(3):452–456.

Bengtson, L. G., P. L. Lutsey, L. R. Loehr, A. Kucharska-Newton, L. Y. Chen, A. M. Chamberlain, L. M. Wruck, S. Duval, S. C. Stearns, and A. Alonso. 2014. Impact of atrial fibrillation on healthcare utilization in the community: The atherosclerosis risk in communities study. *Journal of the American Heart Association* 3(6):e001006.

Berchialla, P., F. Foltran, A. Di Lenarda, G. Barbati, L. Franchin, L. Salvatore, and D. Gregori. 2010. Hospitalization rate as a proxy for the quality of life evaluation: The case of dilated cardiomiopathy. *Journal of Preventive Medicine and Hygiene* 51(4):152–156.

Betihavas, V., S. A. Frost, P. J. Newton, P. Macdonald, S. Stewart, M. J. Carrington, Y. K. Chan, and P. M. Davidson. 2015. An absolute risk prediction model to determine unplanned cardiovascular readmissions for adults with chronic heart failure. *Heart, Lung and Circulation* 24(11):1068–1073.

Bibbins-Domingo, K., M. J. Pletcher, F. Lin, E. Vittinghoff, J. M. Gardin, A. Arynchyn, C. E. Lewis, O. D. Williams, and S. B. Hulley. 2009. Racial differences in incident heart failure among young adults. *New England Journal of Medicine* 360(12):1179–1190.

Bolge, S. C., V. N. Joish, R. Balkrishnan, H. Kannan, and C. L. Drake. 2010. Burden of chronic sleep maintenance insomnia characterized by nighttime awakenings. *Population Health Management* 13(1):15–20.

Bradley, C. J., and H. L. Bednarek. 2002. Employment patterns of long-term cancer survivors. *Psychooncology* 11(3):188–198.

Braithwaite, D., W. A. Satariano, B. Sternfeld, R. A. Hiatt, P. A. Ganz, K. Kerlikowske, D. H. Moore, M. L. Slattery, M. Tammemagi, A. Castillo, M. Melisko, L. Esserman, E. K. Weltzien, and B. J. Caan. 2010. Long-term prognostic role of functional limitations among women with breast cancer. *Journal of the National Cancer Institute* 102(19):1468–1477.

Brousseau, D. C., P. L. Owens, A. L. Mosso, J. A. Panepinto, and C. A. Steiner. 2010. Acute care utilization and rehospitalizations for sickle cell disease. *JAMA* 303(13):1288–1294.

Brown, J. R., C. R. Parikh, C. S. Ross, R. S. Kramer, P. C. Magnus, K. Chaisson, R. A. Boss, Jr., R. E. Helm, S. R. Horton, P. Hofmaster, H. Desaulniers, P. Blajda, B. M. Westbrook, D. Duquette, K. LeBlond, R. D. Quinn, C. Jones, A. W. DiScipio, and D. J. Malenka. 2014. Impact of perioperative acute kidney injury as a severity index for thirty-day readmission after cardiac surgery. *The Annals of Thoracic Surgery* 97(1):111–117.

Calvillo-King, L., D. Arnold, K. J. Eubank, M. Lo, P. Yunyongying, H. Stieglitz, and E. A. Halm. 2013. Impact of social factors on risk of readmission or mortality in pneumonia and heart failure: Systematic review. *Journal of General Internal Medicine* 28(2):269–282.

Chamberlain, A. M., S. J. Bielinski, S. A. Weston, W. Klaskala, R. M. Mills, B. J. Gersh, A. Alonso, and V. L. Roger. 2013. Atrial fibrillation in myocardial infarction patients: Impact on health care utilization. *American Heart Journal* 166(4):753–759.

Charlton, M. E., K. B. Stitzenberg, C. Lin, J. A. Schlichting, T. R. Halfdanarson, G. Y. Juarez, J. F. Pendergast, E. A. Chrischilles, and R. B. Wallace. 2015. Predictors of long-term quality of life for survivors of stage 2/3 rectal cancer in the cancer care outcomes research and surveillance consortium. *Journal of Oncology Practice* 11(4):e476–e486.

Choi, B. Y., D. M. DiNitto, C. N. Marti, and N. G. Choi. 2016. Impact of mental health and substance use disorders on emergency department visit outcomes for HIV patients. *The Western Journal of Emergency Medicine* 17(2):153–164.

Collie, A., and K. H. Prang. 2013. Patterns of healthcare service utilisation following severe traumatic brain injury: An idiographic analysis of injury compensation claims data. *Injury* 44(11):1514–1520.

Creber, R. M., R. Polomano, J. Farrar, and B. Riegel. 2012. Psychometric properties of the Kansas City Cardiomyopathy Questionnaire (KCCQ). European Journal of Cardiiovasculoar Nursing 11(2):197–206.

Derogatis, L. R. 1993. *Brief symptom inventory: Administration, scoring, and procedures manual*. Minnesota: National Computer Systems.

Deutsch, M. A., S. Bleiziffer, Y. Elhmidi, N. Piazza, B. Voss, R. Lange, and M. Krane. 2013. Beyond adding years to life: Health-related quality-of-life and functional outcomes in patients with severe aortic valve stenosis at high surgical risk undergoing transcatheter aortic valve replacement. *Current Cardiology Reviews* 9(4):281–294.

Dudekula, A., M. O'Connell, and K. Bielefeldt. 2011. Hospitalizations and testing in gastroparesis. *Journal of Gastroenterology and Hepatology* 26(8):1275–1282.

Ekberg-Aronsson, M., K. Lofdahl, J. A. Nilsson, C. G. Lofdahl, and P. M. Nilsson. 2008. Hospital admission rates among men and women with symptoms of chronic bronchitis and airflow limitation corresponding to the gold stages of chronic obstructive pulmonary disease—a population-based study. *Respiratory Medicine* 102(1):109–120.

Everhart, J. E., and C. E. Ruhl. 2009. Burden of digestive diseases in the United States part iii: Liver, biliary tract, and pancreas. *Gastroenterology* 136(4):1134–1144.

Fan, A. Z., T. W. Strine, R. Jiles, J. T. Berry, and A. H. Mokdad. 2009. Psychological distress, use of rehabilitation services, and disability status among noninstitutionalized US adults aged 35 years and older, who have cardiovascular conditions, 2007. *International Journal of Public Health* 54 (Suppl 1):100–105.

Fan, V. S., S. D. Ramsey, B. J. Make, and F. J. Martinez. 2007. Physiologic variables and functional status independently predict COPD hospitalizations and emergency department visits in patients with severe COPD. *Journal of Chronic Obstructive Pulmonary Disease* 4(1):29–39.

Farrell, R. T., R. L. Gamelli, R. F. Aleem, and J. M. Sinacore. 2008. The relationship of body mass index and functional outcomes in patients with acute burns. *Journal of Burn Care & Research* 29(1):102–108.

Farris, M. S., K. A. Kopciuk, K. S. Courneya, S. E. McGregor, Q. Wang, and C. M. Friedenreich. 2017. Identification and prediction of health-related quality of life trajectories after a prostate cancer diagnosis. *International Journal of Cancer* 140(7):1517–1527.

Fielden, S. J., M. L. Rusch, B. Yip, E. Wood, K. Shannon, A. R. Levy, J. S. Montaner, and R. S. Hogg. 2008. Nonadherence increases the risk of hospitalization among HIV-infected antiretroviral naive patients started on HAART. *Journal of the International Association of Physicians in AIDS Care* 7(5):238–244.

Finlayson, T. L., C. A. Moyer, and S. S. Sonnad. 2004. Assessing symptoms, disease severity, and quality of life in the clinical context: A theoretical framework. *American Journal of Managed Care* 10(5):336–344.

Foraker, R. E., K. M. Rose, C. M. Suchindran, P. P. Chang, A. M. McNeill, and W. D. Rosamond. 2011. Socioeconomic status, Medicaid coverage, clinical comorbidity, and rehospitalization or death after an incident heart failure hospitalization: Atherosclerosis risk in communities cohort (1987 to 2004). *Circulation: Heart Failure* 4(3):308–316.

Forslund, M. V., C. Roe, J. C. Arango-Lasprilla, S. Sigurdardottir, and N. Andelic. 2013. Impact of personal and environmental factors on employment outcome two years after moderate-to-severe traumatic brain injury. *Journal of Rehabilitation Medicine* 45(8):801–807.

Gambassi, G., S. A. Agha, X. Sui, C. W. Yancy, J. Butler, G. Giamouzis, T. E. Love, and A. Ahmed. 2008. Race and the natural history of chronic heart failure: A propensity-matched study. *Journal of Cardiac Failure* 14(5):373–378.

Hewitt, M., J. H. Rowland, and R. Yancik. 2003. Cancer survivors in the United States: Age, health, and disability. *The Journals of Gerontology. Series A, Biological Sciences and Medical Sciences* 58(1):82–91.

Izano, M., W. A. Satariano, R. A. Hiatt, and D. Braithwaite. 2013. The impact of functional limitations on long-term outcomes among African-American and white women with breast cancer: A cohort study. *British Medical Journal Open* 3(10):e003232.

Izano, M., W. A. Satariano, M. C. Tammemagi, D. Ragland, D. H. Moore, E. Allen, A. Naeim, M. E. Sehl, R. A. Hiatt, K. Kerlikowske, O. Sofrygin, and D. Braithwaite. 2014. Long-term outcomes among African-American and white women with breast cancer: What is the impact of comorbidity? *Journal of Geriatric Oncology* 5(3):266–275.

Jaap, K., M. Hunsinger, J. Dove, K. McGinty, E. Stefanowicz, J. Fera, J. Wild, M. Shabahang, and J. Blansfield. 2016. Morphometric predictors of morbidity after pancreatectomy. *The American Surgeon* 82(12):1221–1226.

Jang, D. B., S. D. Shin, Y. S. Ro, K. J. Song, K. O. Ahn, S. S. Hwang, Y. T. Kim, S. O. Hong, and J. A. Choi. 2016. Interaction of the diabetes mellitus and cardiac diseases on survival outcomes in out-of-hospital cardiac arrest. *American Journal of Emergency Medicine* 34(4):702–707.

Jones, E., J. Pike, T. Marshall, and X. Ye. 2016. Quantifying the relationship between increased disability and health care resource utilization, quality of life, work productivity, health care costs in patients with multiple sclerosis in the US. *BMC Health Services Research* 16:294.

Josephs, J. S., J. A. Fleishman, P. T. Korthuis, R. D. Moore, and K. A. Gebo. 2010. Emergency department utilization among HIV-infected patients in a multisite multistate study. *HIV Medicine* 11(1):74–84.

Karhade, A. V., V. S. Vasudeva, H. H. Dasenbrock, Y. Lu, W. B. Gormley, M. W. Groff, J. H. Chi, and T. R. Smith. 2016. Thirty-day readmission and reoperation after surgery for spinal tumors: A national surgical quality improvement program analysis. *Neurosurgical Focus* 41(2):E5.

Katon, W. J., B. A. Young, J. Russo, E. H. Lin, P. Ciechanowski, E. J. Ludman, and M. R. Von Korff. 2013. Association of depression with increased risk of severe hypoglycemic episodes in patients with diabetes. *The Annals of Family Medicine* 11(3):245–250.

Kerr, J. C., T. G. Stephens, J. J. Gibson, and W. A. Duffus. 2012. Risk factors associated with inpatient hospital utilization in HIV-positive individuals and relationship to HIV care engagement. *Journal of Acquired Immune Deficiency Syndromes* 60(2):173–182.

Kim, M. H., J. Lin, M. Hussein, and D. Battleman. 2009. Incidence and economic burden of suspected adverse events and adverse event monitoring during AF therapy. *Current Medical Research and Opinion* 25(12):3037–3047.

Kimball, A. B., J. Schenfeld, N. A. Accortt, M. S. Anthony, K. J. Rothman, and D. Pariser. 2014. Incidence rates of malignancies and hospitalized infectious events in patients with psoriasis with or without treatment and a general population in the U.S.A.: 2005–09. *British Journal of Dermatology* 170(2):366–373.

Korsnes, J. S., K. L. Davis, R. Ariely, C. F. Bell, and D. Mitra. 2015. Health care resource utilization and costs associated with nonfatal major adverse cardiovascular events. *Journal of Managed Care & Specialty Pharmacy* 21(6):443–450.

Lanfear, D. E., E. L. Peterson, J. Campbell, H. Phatak, D. Wu, K. Wells, J. A. Spertus, and L. K. Williams. 2011. Relation of worsened renal function during hospitalization for heart failure to long-term outcomes and rehospitalization. *American Journal of Cardiology* 107(1):74–78.

Leschke, J., J. A. Panepinto, M. Nimmer, R. G. Hoffmann, K. Yan, and D. C. Brousseau. 2012. Outpatient follow-up and rehospitalizations for sickle cell disease patients. *Pediatric Blood Cancer* 58(3):406–409.

Libby, A. M., V. Ghushchyan, R. B. McQueen, J. F. Slejko, J. L. Bainbridge, and J. D. Campbell. 2012. Economic differences in direct and indirect costs between people with epilepsy and without epilepsy. *Medical Care* 50(11):928–933.

Lipscomb, H. J., A. L. Schoenfisch, W. Cameron, K. L. Kucera, D. Adams, and B. A. Silverstein. 2015. Contrasting patterns of care for musculoskeletal disorders and injuries of the upper extremity and knee through workers' compensation and private health care insurance among union carpenters in Washington state, 1989 to 2008. *American Journal of Industrial Medicine* 58(9):955–963.

McKee, M. M., P. C. Winters, A. Sen, P. Zazove, and K. Fiscella. 2015. Emergency department utilization among deaf American sign language users. *Disability and Health Journal* 8(4):573–578.

Menendez, M. E., and D. Ring. 2015. Factors associated with hospital admission for proximal humerus fracture. *American Journal of Emergency Medicine* 33(2):155–158.

Merchant, S. J., P. H. Ituarte, A. Choi, V. Sun, J. Chao, B. Lee, and J. Kim. 2015. Hospital readmission following surgery for gastric cancer: Frequency, timing, etiologies, and survival. *Journal of Gastrointestinal Surgery* 19(10):1769–1781.

Mizutani, K., M. Hara, S. Iwata, T. Murakami, T. Shibata, M. Yoshiyama, T. Naganuma, F. Yamanaka, A. Higashimori, N. Tada, K. Takagi, M. Araki, H. Ueno, M. Tabata, S. Shirai, Y. Watanabe, M. Yamamoto, and K. Hayashida. 2017. Elevation of b-type natriuretic peptide at discharge is associated with 2-year mortality after transcatheter aortic valve replacement in patients with severe aortic stenosis: Insights from a multicenter prospective ocean-tavi (optimized transcatheter valvular intervention-transcatheter aortic valve implantation) registry. *Journal of the American Heart Association* 6(7).

Mullady, D. K., D. Yadav, S. T. Amann, M. R. O'Connell, M. M. Barmada, G. H. Elta, J. M. Scheiman, E. J. Wamsteker, W. D. Chey, M. L. Korneffel, B. M. Weinman, A. Slivka, S. Sherman, R. H. Hawes, R. E. Brand, F. R. Burton, M. D. Lewis, T. B. Gardner, A. Gelrud, J. DiSario, J. Baillie, P. A. Banks, D. C. Whitcomb, M. A. Anderson, and N. Consortium. 2011. Type of pain, pain-associated complications, quality of life, disability and resource utilisation in chronic pancreatitis: A prospective cohort study. *Gut* 60(1):77–84.

Mullerova, H., D. J. Maselli, N. Locantore, J. Vestbo, J. R. Hurst, J. A. Wedzicha, P. Bakke, A. Agusti, and A. Anzueto. 2015. Hospitalized exacerbations of COPD: Risk factors and outcomes in the eclipse cohort. *Chest* 147(4):999–1007.

Myer, P. A., A. Mannalithara, G. Singh, G. Singh, P. J. Pasricha, and U. Ladabaum. 2013. Clinical and economic burden of emergency department visits due to gastrointestinal diseases in the United States. *American Journal of Gastroenterology* 108(9):1496–1507.

Nadjiri, J., J. Hausleiter, S. Deseive, A. Will, E. Hendrich, S. Martinoff, and M. Hadamitzky. 2016. Prognostic value of coronary ct angiography in diabetic patients: A 5-year follow up study. *International Journal of Cardiovascular Imaging* 32(3):483–491.

Naz, B., T. J. Craig, E. J. Bromet, S. J. Finch, L. J. Fochtmann, and G. A. Carlson. 2007. Remission and relapse after the first hospital admission in psychotic depression: A 4-year naturalistic follow-up. *Psychological Medicine* 37(8):1173–1181.

Nemunaitis, G., M. J. Roach, J. Claridge, and M. Mejia. 2016. Early predictors of functional outcome after trauma. *PM & R : The Journal of Injury, Function, and Rehabilitation* 8(4):314–320.

Opolski, G., L. Januszkiewicz, E. Szczerba, B. Osinska, D. Rutkowski, Z. Kalarus, and J. Kazmierczak. 2015. Readmissions and repeat procedures after catheter ablation for atrial fibrillation. *Cardiology Journal* 22(6):630–636.

Palma, A., D. W. Lounsbury, L. Messer, and E. B. Quinlivan. 2015. Patterns of HIV service use and HIV viral suppression among patients treated in an academic infectious diseases clinic in North Carolina. *AIDS and Behavior* 19(4):694–703.

Panopalis, P., J. Z. Gillis, J. Yazdany, L. Trupin, A. Hersh, L. Julian, L. A. Criswell, P. Katz, and E. Yelin. 2010. Frequent use of the emergency department among persons with systemic lupus erythematosus. *Arthritis Care and Research: The Official Journal of the Arthritis Health Professions Association* 62(3):401–408.

Pendleton, A. M., L. K. Cannada, and M. Guerrero-Bejarano. 2007. Factors affecting length of stay after isolated femoral shaft fractures. *Journal of Trauma and Acute Care Surgery* 62(3):697–700.

Perkins, R. M., A. Rahman, I. D. Bucaloiu, E. Norfolk, W. DiFilippo, J. E. Hartle, and H. L. Kirchner. 2013. Readmission after hospitalization for heart failure among patients with chronic kidney disease: A prediction model. *Clinical Nephrology* 80(6):433–440.

Powars, D. R., L. S. Chan, A. Hiti, E. Ramicone, and C. Johnson. 2005. Outcome of sickle cell anemia: A 4-decade observational study of 1056 patients. *Medicine (Baltimore)* 84(6):363–376.

Quintana, J. M., A. Unzurrunzaga, S. Garcia-Gutierrez, N. Gonzalez, I. Lafuente, M. Bare, N. F. de Larrea, F. Rivas, and C. Esteban. 2015. Predictors of hospital length of stay in patients with exacerbations of COPD: A cohort study. *Journal of General Internal Medicine* 30(6):824–831.

Rahman, R., P. J. Catalano, D. A. Reardon, A. D. Norden, P. Y. Wen, E. Q. Lee, L. Nayak, R. Beroukhim, I. F. Dunn, A. J. Golby, M. D. Johnson, E. A. Chiocca, E. B. Claus, B. M. Alexander, and N. D. Arvold. 2015. Incidence, risk factors, and reasons for hospitalization among glioblastoma patients receiving chemoradiation. *Journal of Neuro-Oncology* 124(1):137–146.

Rosenheck, R. A., S. E. Estroff, K. Sint, H. Lin, K. T. Mueser, D. G. Robinson, N. R. Schooler, P. Marcy, and J. M. Kane. 2017. Incomes and outcomes: Social Security disability benefits in first-episode psychosis. *American Journal of Psychiatry* 174(9):886–894.

Sanders, K. A., S. M. Labott, R. Molokie, S. R. Shelby, and J. Desimone. 2010. Pain, coping and health care utilization in younger and older adults with sickle cell disease. *Journal of Health Psychology* 15(1):131–137.

Sharif, R., T. M. Parekh, K. S. Pierson, Y. F. Kuo, and G. Sharma. 2014. Predictors of early readmission among patients 40 to 64 years of age hospitalized for chronic obstructive pulmonary disease. *Annals of the American Thoracic Society* 11(5):685–694.

Sharma, A., D. M. Sharp, L. G. Walker, and J. R. Monson. 2007. Predictors of early postoperative quality of life after elective resection for colorectal cancer. *Annals of Surgical Oncology* 14(12):3435–3442.

Short, P. F., J. J. Vasey, and R. Belue. 2008. Work disability associated with cancer survivorship and other chronic conditions. *Psychooncology* 17(1):91–97.

Siebert, U., J. Wurm, R. M. Gothe, M. Arvandi, S. R. Vavricka, R. von Kanel, S. Begre, M. C. Sulz, C. Meyenberger, and M. Sagmeister. 2013. Predictors of temporary and permanent work disability in patients with inflammatory bowel disease: Results of the Swiss inflammatory bowel disease cohort study. *Inflammatory Bowel Diseases* 19(4):847–855.

SSA (Social Security Administration). 2017. *Substantial gainful activity*. https://www.ssa.gov/oact/cola/sga.html (accessed May 27, 2017).

Thomas, K. C., and A. R. Ellis. 2013. Patterns of healthcare use and employment among people with disabilities. *Disability and Health Journal* 6(2):133–140.

Thomas, K. L., A. F. Hernandez, D. Dai, P. Heidenreich, G. C. Fonarow, E. D. Peterson, and C. W. Yancy. 2011. Association of race/ethnicity with clinical risk factors, quality of care, and acute outcomes in patients hospitalized with heart failure. *American Heart Journal* 161(4):746–754.

Thorpe, R. J., Jr., A. J. Wynn, J. L. Walker, J. R. Smolen, M. P. Cary, S. L. Szanton, and K. E. Whitfield. 2016. Relationship between chronic conditions and disability in African American men and women. *Journal of the National Medical Association* 108(1):90–98.

Towfighi, A., D. Markovic, and B. Ovbiagele. 2011. National gender-specific trends in myocardial infarction hospitalization rates among patients aged 35 to 64 years. *American Journal of Cardiology* 108(8):1102–1107.

van der Linde, D., E. R. Andrinopoulou, E. N. Oechslin, W. Budts, A. P. van Dijk, P. G. Pieper, E. M. Wajon, M. C. Post, M. Witsenburg, C. K. Silversides, A. Oxenius, A. J. Bogers, J. J. Takkenberg, and J. W. Roos-Hesselink. 2013. Congenital valvular aortic stenosis in young adults: Predictors for rate of progression of stenosis and aortic dilatation. *International Journal of Cardiology* 168(2):863–870.

Vestbo, J., W. Anderson, H. O. Coxson, C. Crim, F. Dawber, L. Edwards, G. Hagan, K. Knobil, D. A. Lomas, W. MacNee, E. K. Silverman, and R. Tal-Singer. 2008. Evaluation of COPD longitudinally to identify predictive surrogate end-points (eclipse). *The European Respiratory Journal* 31(4):869–873.

Wahlqvist, P., M. Karlsson, D. Johnson, J. Carlsson, S. C. Bolge, and M. A. Wallander. 2008. Relationship between symptom load of gastro-oesophageal reflux disease and health-related quality of life, work productivity, resource utilization and concomitant diseases: Survey of a US cohort. *Alimentary Pharmacology & Therapeutics* 27(10):960–970.

Wolfson, J. A., S. M. Schrager, T. D. Coates, and M. D. Kipke. 2011. Sickle-cell disease in California: A population-based description of emergency department utilization. *Pediatric Blood & Cancer* 56(3):413–419.

Wolfson, J. A., S. M. Schrager, R. Khanna, T. D. Coates, and M. D. Kipke. 2012. Sickle cell disease in California: Sociodemographic predictors of emergency department utilization. *Pediatric Blood & Cancer* 58(1):66–73.

Yabroff, K. R., W. F. Lawrence, S. Clauser, W. W. Davis, and M. L. Brown. 2004. Burden of illness in cancer survivors: Findings from a population-based national sample. *Journal of the National Cancer Institute* 96(17):1322–1330.

Yamada, S., Y. Shimizu, M. Suzuki, and T. Izumi. 2012. Functional limitations predict the risk of rehospitalization among patients with chronic heart failure. *Circulation Journal* 76(7):1654–1661.

Yazdany, J., B. J. Marafino, M. L. Dean, N. S. Bardach, R. Duseja, M. M. Ward, and R. A. Dudley. 2014. Thirty-day hospital readmissions in systemic lupus erythematosus: Predictors and hospital- and state-level variation. *Arthritis & Rheumatology* 66(10):2828–2836.

Yehia, B. R., J. A. Fleishman, P. L. Hicks, M. Ridore, R. D. Moore, and K. A. Gebo. 2012. Inpatient health services utilization among HIV-infected adult patients in care 2002–2007. *Journal of Acquired Immune Deficiency Syndromes* 53(3):397–404.

Young, A., S. Muhlner, A. Kurowski, and M. Cifuentes. 2015. The association between physical medicine and rehabilitation service utilization and disability duration following work-related fracture. *Work* 51(2):327–336.

Young, A. E., M. Cifuentes, R. Wasiak, and B. S. Webster. 2009. Urban-rural differences in work disability following occupational injury: Are they related to differences in healthcare utilization? *Journal of Occupational and Environmental Medicine* 51(2):204–212.

Zhang, Q., Y. Yang, J.L. Saver. 2015. Discharge destination after acute hospitalization strongly predicts three month disability outcome in ischemic stroke. *Restorative Neurology and Neuroscience* 33(5):771-775.

Glossary

Activities of daily living (ADLs)—Activities related to personal care, including bathing, dressing, getting in or out of bed or chair, using the toilet, and eating.

Ambulatory care—Health services that are provided on an outpatient basis, in contrast to services provided in the home or to persons who are inpatients. Although many inpatients may be ambulatory, the term "ambulatory care" usually implies that the patient must travel to a location to receive services that do not require an overnight stay.

Bundled payment—Strategy for reducing health-care costs that involves reimbursement for multiple providers bundled into a single, comprehensive payment that covers all of the services involved in the patient's care.

Case-control study—A type of observational study where patients with a certain outcome or disease and an appropriate group of controls without the outcome or disease are selected and then information is obtained on whether the subjects have been exposed to the factor under investigation.

Clinic—An administrative unit of a hospital outpatient department where ambulatory medical care is provided under the supervision of a physician.

Cohort study—A type of observational study where data are obtained from groups who have been exposed, or not exposed, to the factor of interest. No allocation of exposure is made by the researcher.

Comorbidities—Conditions that exist at the same time as the primary condition in the same patient.

Cross-sectional study—A type of observational study that examines the relationship between diseases (or other health-related characteristics) and other variables of interest as they exist in a defined population at one particular time.

Disability—The law defines disability as the "inability to engage in any substantial gainful activity (SGA) by reason of any medically determinable physical or mental impairment(s) which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months" (CFR § 404.1505). The American Medical Association (AMA) defines disability as "activity limitations and/or participation restrictions in an individual with a health condition, disorder, or disease."

Emergency department (ED)—An emergency department, also known as an accident and emergency department (A&E), emergency room (ER), emergency ward (EW), or casualty department, is a medical treatment facility specializing in emergency medicine and the acute care of patients who present without prior appointment, either by their own means or by that of an ambulance. The emergency department is usually found in a hospital or other primary care center.

Emergency Medical Treatment and Labor Act (EMTALA)—An act of the US Congress passed in 1986 that ensures public access to emergency services regardless of ability to pay.

Gainful activity—Work activity usually done for pay or profit, whether or not a profit is realized. SSA considers the impairments in the Listing of Impairments to be severe enough to prevent a person from doing any gainful activity, regardless of age, education, or work experience.

Health-care utilization—The use of health-care services for a variety of reasons, including to prevent or cure disease, to reduce pain, to improve quality of life, or simply to obtain more information about health status.

Home health care—Home health care as defined by the National Home and Hospice Care Survey is care provided to individuals and families in their place of residence for promoting, maintaining, or restoring health; or for minimizing the effects of disability and illness, including terminal illness.

Hospital—According to the American Hospital Association, a licensed institution with at least six beds whose primary function is to provide diagnostic and therapeutic patient services for medical conditions by an organized physician staff and has continuous nursing services under the supervision of registered nurses.

Impairment—According to SSA, "an impairment or combination of impairments that significantly limit the individual's physical or mental abilities and, as a result, interfere with the individual's ability to perform basic work activities." The AMA defines impairment as "a significant deviation, loss, or loss of use of any body structure or body function in an individual with a health condition, disorder, or disease."

Instrumental activities of daily living—Activities related to independent living, including preparing meals, managing money, shopping for groceries or personal items, performing light or heavy housework, and using a telephone.

Length of stay—The duration of a single episode of hospitalization, calculated by subtracting the day of admission from the day of discharge.

Listing of Impairments (Listings)—The SSA Listing of Impairments describes, for each major body system, impairments considered severe enough to prevent an individual from doing any gainful activity. The criteria in the Listing of Impairments are applicable to evaluation of claims for disability benefits under the Social Security Disability Insurance program or payments under

the SSI program. The criteria in the Listing of Impairments apply only to one step of the multi-step sequential evaluation process. At that step, the presence of an impairment that meets the criteria in the Listing of Impairments (or that is of equal severity) is usually sufficient to establish that an individual who is not working is disabled. However, the absence of a listing-level impairment does not mean the individual is not disabled. Rather, it merely requires the adjudicator to move on to the next step of the process and apply other rules in order to resolve the issue of disability.

Long-term care—Services and supports necessary to meet health or personal care needs over an extended period of time.

Medicaid—Medicaid provides health coverage to millions of Americans, including eligible low-income adults, children, pregnant women, elderly adults, and people with disabilities. Medicaid is administered by states, according to federal requirements. The program is funded jointly by states and the federal government.

Medical home—Also known as the patient-centered medical home (PCMH). A team-based health-care delivery model led by a health care provider that is intended to provide comprehensive and continuous medical care to patients with the goal of obtaining maximized health outcomes.

Medicare—Administered by the federal government since 1976, Medicare is a single-payer, national social insurance program, which currently uses about 30–50 private insurance companies across the United States. The US Medicare program is funded by a payroll tax, premiums and surtaxes from beneficiaries, and general revenue. It provides health insurance for Americans aged 65 and older who have worked and paid into the system through the payroll tax. It also provides health insurance to younger people with some disabilities status as determined by the Social Security Administration, as well as people with end-stage renal disease and amyotrophic lateral sclerosis.

Negative predictive value (NPV)—The proportion of negative results that are true negatives, i.e., number of true negatives/(number of true negatives + number of false negatives).

Nursing home—An establishment licensed as a nursing home with three or more beds that routinely provides nursing care services. Homes providing only personal or domiciliary care are excluded. Facilities included are either certified by Medicare or Medicaid, or they are not certified but licensed by the state as a nursing home. These facilities may be freestanding or distinct nursing care units of larger facilities.

Outpatient—A patient who is receiving ambulatory care at a hospital or other facility that also provides inpatient care without being admitted to the facility.

Patient Protection and Affordable Care Act (ACA)—A US federal statute designed to increase health insurance quality and affordability, lower the uninsured rate, and reduce costs of health care. Signed into law on March 23, 2010.

Positive predictive value (PPV)—The proportion of positive results that are true positives, i.e., number of true positives/(number of true positives + number of false positives).

Randomized controlled trial (RCT)—An experimental comparison study in which participants are allocated to treatment/intervention or control/placebo groups using a random mechanism.

Readmission—An episode when a patient who had been discharged from a hospital is admitted again within a specified time interval.

Receiver operating characteristic (ROC) curve—A plot of the true positive rate against the false positive rate for the possible cut points of a diagnostic test, to demonstrate tradeoff between sensitivity and specificity, and to examine the accuracy of the test.

Sensitivity—The proportion of positives that are correctly identified as such, i.e., true positives/(true positives + false negatives).

Severe impairment—According to the Social Security Administration, "At step 2 of the sequential evaluation process, an impairment or combination of impairments is considered 'severe' if it significantly limits an individual's physical or mental abilities to do basic work activities."

Skilled care—Nursing care such as help with medications and caring for wounds, and therapies such as occupational, speech, respiratory, and physical therapy. Skilled care usually requires the services of a licensed professional such as a nurse, doctor, or therapist.

Social Security Disability Insurance (SSDI)— The SSDI program provides disability benefits to people who are under the full retirement age and are no longer able to work because of a disabling medical condition or because they have a terminal illness.

Specificity—The proportion of negatives that are correctly identified as such, i.e., true negatives/(true negatives + false positives).

Substantial gainful activity (SGA)—Work activity, that involves doing significant physical or mental activities, usually done for pay or profit, whether or not a profit is realized. According to the Social Security Administration, "a person who is earning more than a certain monthly amount (net of impairment-related work expenses) is ordinarily considered to be engaging in SGA. The amount of monthly earnings considered as SGA depends on the nature of a person's disability. The Social Security Act specifies a higher SGA amount for statutorily blind individuals; Federal regulations specify a lower SGA amount for non-blind individuals. Both SGA amounts generally change with changes in the national average wage index."

Supplemental Security Income (SSI)—The SSI program is a means-tested income-assistance program for disabled, blind, and aged people who have limited income and resources regardless of their prior participation in the labor force.

Systematic evidence review—Scientific investigation that focuses on a specific question and uses explicit, preplanned scientific methods to identify, select, assess, and summarize the findings of individual, relevant studies.

Technology-based health—The use of mobile technologies to provide individual-level interventions to consumers for health care, for example, text messaging interventions to increase medication adherence.

Telehealth—Technologies and tactics used to virtually deliver health-care and health education services, including telemedicine, which refers to traditional clinical diagnosis and monitoring administered through technological platforms.