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THE NATIONAL ACADEMIES Advisers to the Nation on Science, Engineering, and Medicine

# Capturing Social and Behavioral Domains in Electronic Health Records

### PHASE 1

Committee on the Recommended Social and Behavioral Domains and Measures for Electronic Health Records

Board on Population Health and Public Health Practice

INSTITUTE OF MEDICINE OF THE NATIONAL ACADEMIES

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The serpent has been a symbol of long life, healing, and knowledge among almost all cultures and religions since the beginning of recorded history. The serpent adopted as a logotype by the Institute of Medicine is a relief carving from ancient Greece, now held by the Staatliche Museen in Berlin.

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This report has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the National Research Council's Report Review Committee. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published report as sound as possible and to ensure that the report meets institutional standards for 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 wish to thank the following individuals for their review of this report:

George J. Isham, Health Partners, Inc. Kenneth W. Kizer, University of California, Davis Michael Lesk, Rutgers, the State University of New Jersey Tracy Lieu, Kaiser Permanente Northern California Bruce G. Link, Columbia University James M. Mold, University of Oklahoma Health Science Center Martin Jose Sepúlveda, IBM Corporation Antonia M. Villarruel, University of Michigan School of Nursing

Although the reviewers listed above have provided many constructive comments and suggestions, they were not asked to endorse the conclusions or recommendations nor did they see the final draft of the report before its release. The review of this report was overseen by **Robert S. Lawrence**,

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### REVIEWERS

Center for a Livable Future, John Hopkins Bloomberg School of Public Health, and **Susan J. Curry**, College of Public Health, University of Iowa. Appointed by the National Research Council and the Institute of Medicine, they were responsible for making certain that an independent examination of this report was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this report rests entirely with the authoring committee and the institution.

# Acknowledgments

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# Summary

### BACKGROUND

Substantial empirical evidence of the contribution of social and behavioral factors to functional status and the onset and progression of disease has accumulated over the past few decades. Traditionally, research and interventions on social and behavioral determinants of health have largely been the purview of public health which has focused on disease prevention and maintenance of the public's health. Health care systems, in contrast, have focused primarily on the treatment of disease in individual patients, and, until recently, social determinants of health have not been linked to clinical practice or health care delivery systems. Electronic health records (EHRs) provide crucial information to providers treating individual patients, to health systems, including public health officials, about the health of populations, and to researchers about the determinants of health and the effectiveness of treatment. Inclusion of social and behavioral health domains in EHRs is vital to all three uses.

The Health Information Technology for Economic and Clinical Health (HITECH) Act<sup>1</sup> and the Patient Protection and Affordable Care Act<sup>2</sup> place new importance on the widespread adoption and meaningful use of EHRs. "Meaningful use" in a health information technology context refers to the use of EHRs and related technology within a health care organization to achieve specified objectives. Achieving meaningful use also helps determine

<sup>&</sup>lt;sup>1</sup> Public Law 111-5.

<sup>&</sup>lt;sup>2</sup> Public Law 111-148.

whether an organization can receive payments from the Medicare EHR Incentive Program or the Medicaid EHR Incentive Program.

The Centers for Medicare & Medicaid Services (CMS) is working with the Office of the National Coordinator for Health Information Technology (ONC) and other parts of the U.S. Department of Health and Human Services to establish regulations for the third stage of the meaningful use incentive program. Meaningful Use Stage 3 is in development and implementation for this stage is expected to start in 2017.

Expansion beyond the traditional medical information collected in EHRs to include social and behavioral health determinants requires the identification and application of criteria for determining what domains should be included in all EHRs and for specific populations. The rapid adoption of EHRs and the exigent Meaningful Use Stage 3 criteria formulation by the ONC and CMS add urgency to this effort.

### THE FORMATION AND CHARGE TO THE COMMITTEE

The Office of Behavioral and Social Sciences Research and other institutes of the National Institutes of Health partnered with the Association of State and Territorial Health Officials, Blue Shield of California Foundation, California HealthCare Foundation, Centers for Disease Control and Prevention, CMS, The Lisa and John Pritzker Family Fund, the Robert Wood Johnson Foundation, and the Substance Abuse and Mental Health Services Administration requested that the Institute of Medicine (IOM) conduct a two-phase study. This first report is intended to inform and aid the ONC and CMS in finalizing domains for Meaningful Use Stage 3. The charge to the committee for the project is presented in Box S-1.

In response to that request, the IOM convened a committee of 13 members with a wide variety of expertise, including leaders from the field of health information technology, social determinants of health, behavioral and psychological issues, and measurement.

### THE COMMITTEE'S APPROACH TO ITS CHARGE

To meet its charge, the committee first established the rationale for adding social and behavioral determinants of health into EHRs and considered how EHRs may assist providers in their decision making, resulting in improved health outcomes for their patients, regardless of Meaningful Use adoption and implementation. The committee held two informationgathering meetings to clarify its statement of task; learn about Meaningful Use objectives; and hear from other experts in the field, stakeholders, and the public on domains that the committee should consider. (See meeting

### SUMMARY

### BOX S-1 Statement of Task

The Institute of Medicine will convene a committee to identify domains and measures that capture the social determinants of health to inform the development of recommendations for Stage 3 meaningful use of electronic health records (EHRs). The committee's work will be conducted in two phases and will produce two products. As part of its work, the committee will:

### Phase 1 (accomplished in this report)

- 1. Identify specific domains to be considered by the Office of the National Coordinator,
- 2. Specify criteria that should be used in deciding which domains should be included,
- 3. Identify core social and behavioral domains to be included in all EHRs, and
- Identify any domains that should be included for specific populations or settings defined by age, socioeconomic status, race/ethnicity, disease, or other characteristics.

A brief Phase 1 report will be produced and submitted to the sponsors by the end of March 2014.

### Phase 2 (to be addressed in a forthcoming report)

The committee will consider the following questions:

- 1. What specific measures under each domain specified in Phase 1 should be included in EHRs? The committee will examine both data elements and mechanisms for data collection.
- 2. What are the obstacles to adding these measures to the EHR and how can these obstacles be overcome?
- 3. What are the possibilities for linking EHRs to public health departments, social service agencies, or other relevant non-health care organizations? Identify case studies, if possible, of where this has been done and how issues of privacy have been addressed.

A final report that includes the Phase 1 report and addresses the Phase 2 questions will be the final product.

The committee will make recommendations where appropriate.

agendas in Appendix A.) After each information-gathering meeting, the committee met in closed session to allow for discussion and deliberation.

Before the first meeting and throughout the study process, the committee reviewed relevant literature. Its formal review of the literature focused on identifying peer-reviewed, published literature and reports, evidence-

### CAPTURING SOCIAL AND BEHAVIORAL DOMAINS IN EHRS

based reviews from governmental agencies, and previous IOM reports that were germane to the statement of task. For this study, the committee uses the term "candidate" to refer to the "core" domains (the third item of the Statement of Task) because the specific task for the Phase 1 report was to identify domains that should be considered by ONC for Stage 3 Meaningful Use. In this context the core domains are those that are "candidates" for being selected for Meaningful Use. The committee erred on the side of inclusion for its Phase 1 report while also trying to limit the number of candidate domains. Consequently, the committee expects to further winnow the list of candidate domains to a smaller number of recommended "core" domains in the Phase 2 report. Throughout the study, the term "domain" is used to refer to determinants of health, which could include health conditions that, in turn, influence other health outcomes.

### DOMAINS AND CRITERIA

Several existing conceptual frameworks identify categories of health determinants and the ways in which they link to mortality as well as to disease onset and progression. These models generally distinguish individual-level characteristics (such as biological factors, emotional and cognitive traits, and health-related behaviors) from features of the context in which they emerge and operate (i.e., the physical and social environment). The committee reviewed a number of existing frameworks and selected three that it used in developing an outline of domains for the committee to review (see Chapter 2) as an initial step in identifying domains to be considered for inclusion in all EHRs.

The committee then decided on the following criteria for domains to be given a high priority for inclusion in EHRs:

- 1. Strength of the evidence of the association of the domain with health.<sup>3</sup>
- 2. Usefulness of the domain, as measured for
  - a. The individual patient for decision making between the clinician and patient for management and treatment;<sup>4</sup>
  - b. The population to describe and monitor population health and making health care-related policy decisions that affect the popu-

<sup>&</sup>lt;sup>3</sup> The committee supports the concept of the World Health Organization's definition of health being a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity. This definition was not originally included in the committee's Phase 1 report.

<sup>&</sup>lt;sup>4</sup> After publication of the Phase 1 report, edits were made to criteria 2.a., to clarify that decision making is between a clinician and a patient, and to criteria 5, to clarify that sensitivity includes legal risk.

### SUMMARY

- c. Research to conduct clinical and population health research to learn about the causes of health, the predictors of outcomes of care, and the impact of interventions at multiple levels.
- 3. Availability and standard representation of a reliable and valid measure(s) of the domain.
- 4. Feasibility, that is, whether a burden is placed on the patient, the clinician and the administrative time and cost of interfaces and storage.
- 5. Sensitivity, that is if patient discomfort regarding revealing personal information is high and there are increased legal or privacy risks.
- 6. Accessibility of data from another source (i.e., information from external sources may be accessible to meet the needs of patient care, population health, and research; if so, the domains would have less priority for inclusion in the EHR).

The committee then worked to narrow the domains in the outline to a smaller number using the first two criteria through a consensus process. The result reduced the number of domains constituting the candidate set for which the committee found sufficient evidence of relevance and utility to consider for inclusion in all EHRs. Given the limited time that the committee had to complete the Phase 1 report in order for its recommendations to be useful for Meaningful Use Stage 3 deliberations, it was not possible to apply the full list of criteria to all of the potential domains before these decisions had to be made. Next, having developed the candidate set, the committee will undertake a fuller evaluation of those domains to achieve a smaller set of recommended domains. This evaluation, which will entail applying the remaining four criteria to the domains, will be reported on in the committee's next report. The committee understands that ONC and CMS will likely need to move forward with their decision making on objectives and measures for Meaningful Use Stage 3 before release of the committee's Phase 2 report. Chapter 3 of the current report and the criteria presented above are intended to serve as resources to support their drafts and final decisions.

### COMMITTEE'S KEY CONCLUSIONS

Identification of a candidate set of domains relevant for all individuals and specific populations was central to the committee's deliberations. While the committee did not identify any specific populations or settings for selected candidate domains, measures for these domains will be identified

### TABLE S-1 Summary of Selected and Non-Selected Domains

,				
Candidate Set of Domains for Consideration for the Inclusion in all Electronic Health Records (Chapter 3)	Domains Reviewed But Not Selected			
Sociodemographic Domains				
<ul> <li>Sexual orientation</li> <li>Race/ethnicity</li> <li>Country of origin/U.S. born or non-U.S. born</li> <li>Education</li> <li>Employment</li> <li>Financial resource strain (Food and housing insecurity)</li> </ul>	• Gender identity			
Psychological Domains				
<ul> <li>Health literacy</li> <li>Stress</li> <li>Negative mood and affect (Depression, anxiety)</li> <li>Psychological assets (Conscientiousness, patient engagement/ activation, optimism, self-efficacy)</li> </ul>	<ul> <li>Negative mood and affect (Hostility and anger, hopelessness)</li> <li>Cognitive function in late life</li> <li>Positive psychological function (Coping, positive affect, life satisfaction)</li> </ul>			
Behavioral Domains				
<ul> <li>Dietary patterns</li> <li>Physical activity</li> <li>Tobacco use and exposure<sup>a</sup></li> <li>Alcohol use</li> </ul>	<ul> <li>Abuse of other substances</li> <li>Sexual practices</li> <li>Exposure to firearms</li> <li>Risk-taking behaviors (Distractive driving and helmet use)</li> </ul>			

in its Phase 2 report and these may be tailored to specific populations, as guided by use of the life course perspective.

The committee's conclusions are listed in Table S-1. Of note, the committee opted to include domains even if they are already routinely captured in EHRs to ensure that they will continue to be prioritized and to allow recommendations for standard measures for these domains as part of the committee's Phase 2 report. The domains are not listed in order of priority, but instead, are organized by the order of the committee's initial outline, which ordered domains in terms of types of data they represented.

### SUMMARY

### TABLE S-1 Continued

Candidate Set of Domains for Consideration for the Inclusion in all Electronic Health Records (Chapter 3)	Domains Reviewed But Not Selected			
Individual-Level Social Relationships Domains				
<ul><li>Social connections and social isolation</li><li>Exposure to violence</li></ul>	<ul> <li>Social support (Emotional, instrumental, and other)</li> <li>Work conditions</li> <li>History of incarceration</li> <li>Military service</li> <li>Community and cultural norms (Health decision making)</li> </ul>			
Neighborhoods and Communities <sup>b</sup>				
<ul> <li>Neighborhood and community compositional characteristics (Socioeconomic and racial/ethnic characteristics)</li> </ul>	• Neighborhood contextual characteristics (Air pollution, allergens, other hazardous exposures, nutritious food options, transportation, parks, open spaces, health care and social services, educational and job opportunities)			

<sup>*a*</sup> The Phase 1 report originally identified the domain as "nicotine use and exposure" but subsequently changed the domain to "tobacco use and exposure."

<sup>b</sup> The original publication in Phase 1 had several editorial errors in the labeling of domains/ subdomains. The report has been updated to correct the errors.

### DOMAINS NOT INCLUDED

In narrowing the initial outline of domains, the committee was faced with challenging decisions that were guided by awareness of the need to identify the domains for which evidence on the association with health outcomes was available and that there would be some utility in having the information in EHRs. Most of the domains excluded from this candidate set simply lacked an adequate evidence base to support routine capture of these data. By limiting the recommended domains to those for which there is a reasonable evidence base, the committee is confident that the list of domains and the measures that follow in the committee's next report, if implemented, will provide crucial data to providers, health systems, and researchers, in turn providing the most appropriate strategies toward improving the health status of Americans. Capturing Social and Behavioral Domains in Electronic Health Records: Phase 1

# Introduction

# SOCIAL AND BEHAVIORAL HEALTH AND PSYCHOLOGICAL DOMAINS

Substantial empirical evidence of the contribution of social and behavioral factors to functional status and the onset and progression of disease has accumulated over the past few decades. Research on social and behavioral determinants of health was inspired to a substantial extent by three landmark papers. The analysis by McGinnis and Foege (1993) of the "actual causes of death" showed the large contribution of behaviors such as smoking, diet and activity, and alcohol as well as socioeconomic status to premature morality. Link and Phelan (1995) argued that social conditions related to socioeconomic resources such as money, social ties, and knowledge are "fundamental causes" of disease. Further, the Whitehall Study of British civil servants (Marmot et al., 1984) demonstrated significant decreases in rates of mortality at each step up in "occupational grade" despite the fact that all of those followed had access to health care. Taken together, these papers provided a compelling argument for examination of the role of social and behavioral factors in the determination of health.

Much of the subsequent research on social conditions and their associated behavioral risks have been aimed at the elimination of avoidable and unjust differences in morbidity and mortality among sociodemographic groups. However, efforts to address health disparities among groups in the United States are not the only reason to consider social and behavioral determinants of health. In the past few years, the relatively poor health status of the U.S. population as a whole relative to that of the populations

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of other countries has fostered interest in understanding the reasons for this situation. The nation lags in life expectancy, maternal mortality, and infant mortality and in the conditions that contribute to these outcomes, including injuries and homicides, sexually transmitted diseases, adolescent pregnancy, heart disease, obesity, diabetes, disability, chronic lung disease, HIV/AIDS, and drug-related mortality (NRC and IOM, 2013). Bradley and Taylor (2013) characterized the fact that the United States has higher rates of morbidity and mortality (CIA, 2011; OECD, 2011a; United Nations, 2009) than other countries of the Organisation for Economic Co-operation and Development (OECD)—even though it spends more on health care than those nations (OECD, 2011b) both in absolute terms and as a portion of the country's gross domestic product—as the American health care paradox.

This unfavorable balance between health care costs and the health of the U.S. population suggests that the way in which the country allocates spending for health care is suboptimal. Some of this may reflect waste and inefficiency in the delivery of health care (Berwick and Hackbarth, 2012; IOM, 2010). However, it may also reflect insufficient attention by the current health care system to the major determinants of health and illness. Increasing evidence indicates that the life conditions outside the encounters with the health care system matter far more than the condition for which a patient seeks care in the exam room. The best available estimates suggests that the conditions for which patients seek medical care (accounting both for access to care and the quality of the care that is received) accounts for only about 10 percent of early deaths, whereas health behaviors and social conditions are estimated to account for more than half of such deaths (McGinnis et al., 2002). In contrast to the OECD countries that Bradley et al. (2011) studied, the United States allocates relatively more of its resources to health care and relatively less on social services. Across all countries, those that had the highest ratio of spending on social services to spending on health care had the best population health statistics.

Traditionally, research and interventions on the social and behavioral determinants of health have largely been the purview of public health, which has focused on prevention of disease and the maintenance of the public's health. Public health researchers and practitioners have long believed that improving the health status of Americans requires addressing the social determinants of health, which are defined as "circumstances in which people are born, grow up, live, work, and age, as well as the health systems they utilize" (CDC, 2013). The goals set for the U.S. population in *Healthy People 2020*, which include improving health status and eliminating disparities, are explicit about the need to address social and physical environments of populations to promote good health and ensure healthy development and behaviors across the life course. Health care systems, in contrast, have pri-

### INTRODUCTION

marily focused on the treatment of disease in individual patients, and until recently, social determinants of health have not been linked in the United States to clinical practice or health care delivery systems. Conversely, several OECD countries incorporate social and behavioral information in their provision of health care and as part of their electronic health record (EHR) (OECD, 2013). The United Kingdom for example, collects information on depression, anxiety, alcohol and tobacco use, as well as physical activity levels (McIntosh et al., 2004; NICE, 2009, 2010, 2013a,b). Countries that are longtime users of EHRs, such as Denmark, New Zealand, and Sweden, have benefited from the interoperable use of patient data. General practitioners and hospitals are able to access patient information, such as physician notes, examinations, prescribed medications, across the health system; and health care facilities are able to plan across primary, secondary, and longterm care settings (Gray et al., 2011).

In recent years, changes have begun in the United States, prompted, in part, by concern about the unsustainability of the growth of health care costs and poor overall public health statistics (NCHS, 2006). This is best exemplified by the conceptualization of the "triple aim" by Berwick et al. (2008). They posit that improvements to health outcomes in the United States require the simultaneous pursuit of improvements to the experience of health care, improvements to the health of populations, and reductions in the per capita costs of health care. These are not independent goals but rely upon each other in the pursuit of achieving high-value health care. The nation's response to the triple aim has resulted in the creation of the National Strategy for Quality Improvement in Health Care that aims to improve the quality of health and health care by aligning public and private interests, in turn, having all parts of the health system working together toward a common goal of improved health for all Americans (HHS, no date).

Changes in policy affecting incentives for new approaches to health care delivery included in the Patient Protection and Affordable Care Act<sup>1</sup> and other policy innovations are encouraging the formation of more coordinated systems that have a greater capacity to address the social and behavioral needs of individual patients and to pay more attention to public health (HHS, no date). Accountable care organizations (ACOs)—groups of doctors, hospitals, and other health care providers, who provide coordinated care to patients—and other group practices are incentivized to maintain the health of the populations that they serve and reduce health care utilization (PwC, 2010). To the extent that the provision of better services and interventions meet their patients' social needs and to eliminate behavioral risk

<sup>&</sup>lt;sup>1</sup> Public Law 111-148.

and reduce the use of health care services, these systems will want to assess the social and behavioral determinants of health.

EHRs hold the potential to serve as essential tools for improving quality, increasing efficiency, and expanding access to the health system (Friedman, 2006; Friedman et al., 2010) They provide crucial information to providers treating individual patients, to health systems about population health, and to researchers about the determinants of health and the effectiveness of treatment. The inclusion of social and behavioral domains in EHRs is vital to all three.

There are inherent risks to collecting personal data in an electronic format. Safeguards have been enacted to counteract potential harms. Health information is protected by a federal law, known as the Health Insurance Portability and Accountability Act of 1996 (HIPAA),<sup>2</sup> which restricts what health care professionals can reveal about their patients' medical status. Given the seriousness of breaches of confidentiality and the extent to which these can undermine the value of EHRs, electronic information must be well-protected in a vigorous manner. Further, for EHRs to achieve their full potential, data will need to be collected consistently across the nation. This requires a commitment from all components in a health system—including the patient's interest and willingness to provide data, some of which might be considered to be sensitive information to the individual.

### GROWING USE OF ELECTRONIC HEALTH DATA AND EHRs

The patient health record, which traces its origin to the Mayo Clinic (Melton, 1996), the Presbyterian Hospital (Lamb, 1955; Openchowski, 1925), and the Flexner Report a century ago (Flexner, 1910), serves "to recall observations, to inform others, to instruct students, to gain knowledge, to monitor performance, and to justify interventions" (Reiser, 1991, p. 902). Early adopters of electronic health data began writing programs to store and retrieve patient records in 1958 (Stead, 1989). By 1991, the Institute of Medicine (IOM) identified the computer-based record as an essential technology for health care (NRC, 1997). Growth of interest in the EHR has paralleled growth in other types of electronic technologies, including mobile communications, online social networks, and sensors.

### DEFINING THE EHR SYSTEM

At many institutions today, the legal health record—which is defined by federal and state regulations—is actually a combination of electronic systems and paper sources. The term EHR loosely refers to the electronic

<sup>&</sup>lt;sup>2</sup> Public Law 104-191, 110 Stat. 1936.

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version of the patient health record, but the term is ambiguous. The "EHR system" comprises both the database that holds the patient information and the software tools used to collect, store, and manage the information, along with the tools needed to support decision making and analyze data (McDonald et al., in press). Therefore, in practice, the EHR refers to those portions of the patient health record that happen to be stored in a particular EHR system. For example, institutions with two EHR systems (e.g., one for inpatient care and one for outpatient care) may split their legal health record into two EHRs. Furthermore, an EHR system is often referred to simply as an "EHR." The term "EHR data" is sometimes used to be clear that the concept refers specifically to the information rather than to the whole system (McDonald et al., in press). Figure 1-1 illustrates the components of an EHR system.

An EHR system's decision-making tools include data-driven alerts and reminders, order sets, displays to visualize information, calculators, list

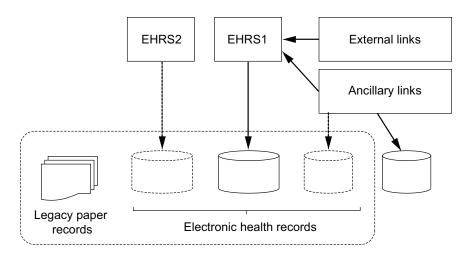


FIGURE 1-1 The legal patient record may comprise electronic and paper information from several sources. In the simplest case, a health provider may be served by a single electronic health record system (EHRS), whose database constitutes the entire legal patient record. Some organizations have more than one EHRS. Ancillary systems such as the clinical laboratory and registration systems have their own databases, which may be considered separate from the legal patient record or may be considered part of it; in addition, they usually upload information to the EHRS's database. There may also be links to outside sources of information, which may upload information or remain purely as a link.

managers, search tools, data validations, and links to knowledge resources (McDonald et al., in press). These tools provide the opportunity to improve decisions and to reduce errors. In the context of social determinants of health, they enable the clinician to efficiently capture the determinants, keep track of them, and apply them at the point of care, incorporating evidence-based practices drawn from recent literature. When it is set up, the EHR system can steer health care practice to use social and behavioral determinants extensively and appropriately to improve health care outcomes (HealthIt.gov, no date–a,b).

EHR systems have, unfortunately, not yet achieved their potential. As of 2009 only 4 to 16 percent of clinicians and hospitals were found to be using EHRs (Blumenthal, 2009; Blumenthal and Tavenner, 2010), with few using truly comprehensive systems. Recent scientific reports include examples of unintentional and adverse clinical consequences in health care settings using EHR systems (Han et al., 2005) because of the discrepancy between health care work and information system design or implementation (Rosenbloom et al., 2006). Still, numerous studies indicate positive results in using EHRs in the following section.

Efforts to recover from the 2008 financial crisis provided an opportunity for improvement. The American Recovery and Reinvestment Act of 2009 (ARRA)<sup>3</sup> included the Health Information Technology for Economic and Clinical Health (HITECH) Act provision, which provided billions of dollars in incentives to use EHR systems to create "significant and measurable improvements" in population health outcomes through a transformed health care delivery system. HITECH required that a certified EHR system be used in a meaningful manner with the electronic exchange of health information and reporting of quality measures. Since 2009, recent published estimates (2012) indicate that 40 percent of office-based physicians have adopted an EHR and 44 percent of hospitals reported having a basic EHR system (RWJF et al., 2013).

### Clinical and Patient Use of EHRs

The inclusion of information on social and behavioral determinants of health in EHRs could direct clinical utility in cases in which knowledge of the condition is relevant to diagnosis, treatment, or prognosis. The data in EHRs are useful tools for health care providers, including hospitals and health care centers, so they may track patient health and illnesses, medical procedures and prognosis, family histories, and laboratory results. Further, EHRs enable computer-based decision support during order entry and prescribing medication. In a study whose findings were published in the

<sup>&</sup>lt;sup>3</sup> Public Law 111-5.

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New England Journal of Medicine, people with diabetes seen by doctors who used EHRs were 35 percent more likely to get all of the recommended screening measures, such as eye exams and blood sugar tests, than patients whose doctors relied on paper records. Moreover, they were 15 percent more likely to have favorable outcomes on those measures (Cebul et al., 2011). Health networks that use common data platforms are also able to share information across health care providers to coordinate patient services. This sharing of patient data allows the health system to efficiently and effectively provide patient care. (See, for example, Box 1-1.) Networks can also use those data to set reminders on when a patient is due for preventive screenings and alerts on contraindications on medications, among other more administrative functions. While numerous challenges exist, the

### BOX 1-1

### The Case of Veronica: Including Community Health Workers, Advocacy Groups, and Citizens to Promote Healthy Neighbors

"Veronica," a patient of Dr. Rishi Manchanda from South Central Los Angeles, had previously sought care at an emergency department (ED) for recurrent and worsening headaches, accompanied by fatigue and malaise. She was given medication for pain and told to return if she did not get better. She returned twice, still in pain. Subsequent workups included a computed tomography (CT) scan, routine blood tests, and a lumbar puncture but revealed nothing clinically wrong. Each of these three ED visits cost more than Veronica's monthly rent. Veronica's headaches persisted; she took more sick days from work and she worried about losing her job and about adequately caring for her young children.

When Veronica came to his clinic, Dr. Manchanda and his colleagues probed further into Veronica's symptoms. The clinic's routine intake process includes the collection of social data on housing. When asked about her living conditions, Veronica revealed that her apartment was damp, infested by roaches, and full of mold. She could not afford to move and the landlord would not repair the leaky plumbing of her small, ground-floor apartment. The diagnosis, Dr. Manchanda thought, was migraine headache triggered by chronic allergies and complicated by sinus congestion. Allergens in the damp apartment also probably accounted for her son's frightening asthma flares, another source of anxiety for Veronica.

The medical staff connected Veronica to a community health worker, who could visit her at home and help her obtain and take the medications she needed to relieve her symptoms. At the same time, she was linked to a tenants' rights advocacy group that petitioned the landlord—this time with a doctor's note in hand—to make the improvements that were in keeping with building codes that were part of his contractual agreements and were in keeping with local building codes. Veronica and her son got better. Veronica had no further ED visits and her needs were fully met in a nearby "patient-centered home" clinic (Manchanda, 2013).

### BOX 1-2 The Case of Sonia: Kaiser Permanente in Northern California's Domestic Violence Program

"Sonia" is a 38-year-old Mexican-American woman who has been married for 20 years, and the mother of two grown children. She has been a long-term hospital employee who had recently been promoted to a supervisory position. At a routine checkup, when the physician asked how things were at home, Sonia shrugged and looked away. A gentle request, "Tell me more," led her to reveal that although she had been separated from her husband for 10 years, he continually terrorized her. She was humiliated that the neighbors had called the police because of his angry shouting. Recently, he had threatened to firebomb her home. When the physician offered a referral to a domestic violence evaluator, Sonia accepted the referral and subsequently joined a support group that she credits for "helping me find a path out of the relationship." She gained confidence to call the police for help, to contact a lawyer, who obtained a restraining order, and then to file for divorce.

Sonia's abusive situation was detected during routine screening for interpersonal violence (IPV). EHR tools such as prompts to screen for IPV, care paths, charting and documentation, and an easily accessible referral protocol facilitate the provision of a caring, effecting, and efficient response to IPV by health care professionals. However, EHR prompts and tools are best paired with appropriate training in order to successfully identify cues, including nonverbal responses (McCaw et al., 2002).

resulting improvement in care coordination, case management, and health care quality this enables will benefit the primary stakeholder—the patient.

Patients, like their health care providers, can use the data in their EHRs to inform themselves and become more involved in their medical care. Patient empowerment plays an integral role in improving quality of care. An informed and actively involved patient can be more engaged in disease self-management and is better able to adhere to the recommendations of his or her health care provider recommendations. Patients who have access to personal health data can obtain their laboratory results, receive drug and appointment alerts, record their nonprescribed medicines and treatments, and can monitor and track their illness treatment and progress, and learn about the prognosis for their illness (Pagliari et al., 2007), potentially resulting in improved quality of care. (See, for example, Box 1-2.)

### Public Health Uses of EHRs

Electronic health data provide valuable information on "the distribution of disease, function, and well-being within a population" (Friedman et

### INTRODUCTION

al., 2013, p. 1560). Perhaps the most common use of EHRs for managing population health is the development of registries that help manage chronic disease and promote prevention. EHRs may provide additional information needed to create a comprehensive public health surveillance system by complementing the data available from existing administrative sources such as the Centers for Medicare & Medicaid Services (CMS) and the Veterans Health Administration (Elliott et al., 2012).

Although many ACOs take a conventional medical approach in viewing their role in managing population health in relation to their panels of patients, others are defining population health as the health of individuals in a geopolitical unit (Hacker and Walker, 2013). Even though both types of ACOs would benefit by incorporating and addressing social and behavioral determinants of health, those with the latter perspective are more likely to incorporate a broader view of the determinants of health including social services, public health, and environmental factors (Noble and Casalino, 2013). An ACO can perhaps best manage community health using data systems that merge clinical data obtained from medical encounters and stored in EHRs with community data obtained from a variety of sources and stored in community information systems. A community information system provides compositional and contextual information about the environments where individuals reside, work, and learn. (See, for example, Box 1-3.) Knowledge of the distribution of community resources and environmental factors that can affect the risk of disease may well become just as important for managing patients' health as knowledge of clinical indicators such as body mass index.

Primary care specialties in the United States have largely endorsed the patient-centered medical home model, which combines the transformation of primary care practice with payment reform to incentivize the core elements of the model. One of the key functions of a patient-centered medical home is the coordination of patient care by helping patients access community resources, facilitating referrals, linking patients to health care and social services, and ensuring the effective transfer of information (Arend et al., 2012; Stange et al., 2010; Wagner et al., 2012).

Integrating social and behavioral determinants of health into EHRs could allow providers and public health agencies to better describe and monitor patterns of heath and outcomes of care for the entire population (Friedman et al., 2013; HealthIT.gov, no date–b). Capturing social determinants of health in EHR data will allow health care providers to better characterize, understand the causes of, and identify appropriate interventions that health systems (and non–health care systems) can make to reduce health disparities (HealthIT.gov, no date–c; ONC, 2013), which will allow critical social problems and also costly problems for the health system and society as a whole to be addressed. The addition of these variables has great

### BOX 1-3 The Case of Benjamin: Sharing EHR Records to Address Health

"Benjamin," a 9-month-old, was hospitalized for difficulty breathing at Cincinnati's Children Hospital and Medical Center. He suffered from respiratory problems, as well as chronic asthma. A resident caring for Benjamin learned that the family had recently filed a complaint with the health department due to mold in their apartment. Rather than make the necessary repairs, the landlord filed to evict Benjamin's family for their complaints. Once this health linkage was discovered, Benjamin was referred to the Cincinnati Child Health Law Partnership (Child HeLP).

The partnership between Cincinnati Children's Hospital and Medical Center and the Legal Aid Society of Greater Cincinnati allows the sharing of information through the patient's EHRs. Once a physician or social worker enters the referral, it is automatically transferred to Child HeLP. Information is seamlessly transferred between physicians and Legal Aid through EHRs, allowing the patient or the patient's family to be well-informed throughout the process.

The Legal Aid Society was able to intervene and stop the family's eviction, and also helped Benjamin's family look for new, safer housing. The family was able to move into a new home where Benjamin is no longer exposed to asthma triggers such as mold (Cincinnati Children's Hospital, 2012).

potential to improve the quality, safety, and efficiency of health services delivery and to support national goals of improving health and eliminating health disparities.

### Research Uses of EHRs

The capture of a core set of standard social and behavioral determinants of health as variables in the EHR advances data harmonization and has the potential to unleash unprecedented opportunities for health research. For example, EHRs can be used to evaluate practice variations and their associations with health outcomes, which in turn will result in improved patient care. Conventional clinical trials, pragmatic clinical trials, clinical epidemiology, and health services research will benefit from enhanced electronic datasets. EHRs can also enable the conduct of registrybased randomized clinical trials (RRCTs), a new form of clinical research trial that takes advantage of computerized patient registries (Lauer and D'Agostino, 2013). These trials are more cost effective than traditional randomized clinical trials because of their more efficient use of time and resources. For example, Fröbert et al. (2013), using the RRCT model,

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evaluated whether routine intracoronary thrombus aspiration (removal of a blood clot within the heart by the use of an aspirator) before primary percutaneous coronary intervention (unblocking of a coronary artery by inflating a balloon, causing a larger opening of the artery) reduced mortality. Michael Lauer, director of cardiovascular sciences for the National Heart, Lung, and Blood Institute, noted that the study was completed at a fraction of the cost (\$300,000) compared with that required for a traditional clinical trial and was completed within a shorter period of time (Lauer and D'Agostino, 2013; National Heart, Lung, and Blood Institute, 2013).

A recent report on precision medicine envisions new taxonomies of diseases defined by their mechanisms and based on the availability of digital information in EHRs linked with genomic and other information (NRC, 2011). The potential for the prevention as well as the treatment of these diseases will be limited, however, if the underlying research fails to include the full range of determinants spanning all the clinical, genetic, epigenetic, and environmental variables that affect health. Social and behavioral data can describe potentially modifiable conditions that, along with clinical and biological data, can provide more preventive, diagnostic, and therapeutic options for improving individual and population health (Barrett et al., 2013).

The social and behavioral information in EHRs can advance both basic and applied research. For example, information on environmental attributes linked to a patient's EHR can facilitate population research on the causal impact of changes in these environmental attributes on behavioral change, biomarkers of risk, and health outcomes. Longitudinal data on patients derived from EHRs will be valuable in establishing causality. This type of evidence is fundamental for establishing policies in a variety of health-related areas. In addition, and perhaps of relevance to practitioners, the availability of this data would enhance clinical research on the extent to which consideration of social and environmental factors are useful in improving the outcomes of care (such as for hypertension and diabetes control). Finally, clinical research on clinician knowledge of these factors may improve diagnosis, treatment, and follow-up; allow better risk stratification; and enhance prediction of outcomes of care.

### **MEANINGFUL USE IN EHRs**

The "Meaningful Use" requirements of HITECH provisions were structured to maximize the effectiveness of EHRs once they are adopted. Professionals and hospitals that are eligible for incentives through HITECH are required to attest to or to measure performance on a series of objectives defined by CMS. The objectives specify EHR system functions and quality measures such as the use of computerized provider order entry, the

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collection of demographic data, and the use of clinical decision support. The objectives are organized into four categories: improve quality, safety, and efficiency and reduce health disparities; engage patients and families; improve care coordination and public health; and ensure adequate privacy and security protections for protected health information (HealthIT.gov, no date–c). The Meaningful Use program was divided into three stages. Stage 1 took effect in 2011, and Stages 2 and 3 (which have been given extensions) are expected to be in place in 2014 and 2017, respectively. As a general guideline, the focus of Stage 1 is data capture and sharing, the focus of Stage 2 is on advancing clinical processes, and the focus of Stage 3 is on improved outcomes (HealthIT.gov, no date–c).

Meaningful Use is defined through a public process. The Meaningful Use Workgroup of the Health Information Technology Policy Committee (HIT Policy Committee) defines a set of objectives and measures for each stage through a series of public meetings. The HIT Policy Committee, which is a federal advisory committee of the Office of the National Coordinator of Health Information Technology (ONC), hears the recommendations of the Meaningful Use Workgroup and other workgroups and tiger teams (an assembled team of specialists) and drafts a letter to ONC with its recommended objectives and measures. ONC shares them with CMS, and ONC and CMS work jointly to define both the Meaningful Use requirements for eligible professionals and hospitals (released by CMS) and the requirements for EHR system certification (released by ONC). A proposed rule is first released, and then a final rule is released after public comment.

Deliberations within the HIT Policy Committee and its workgroups address the balance among moving as quickly as possible because of the urgency of achieving health care reform, the desire to improve patient outcomes, and the timing of incentives (which were front loaded), and moving more slowly because of limited capabilities in currently available EHR systems, the time needed to implement EHR systems, the realities of small clinical practices, and the desire to learn from previous experience with Meaningful Use before new stages are defined.<sup>4</sup> As of October 2013, about one-half of eligible professionals and two-thirds of eligible hospitals had achieved Meaningful Use Stage 1, which represents a huge improvement over the 2009 baseline level of achievement (King and Adler-Milstein, 2013).

Meaningful Use represents a lever that can be used to steer health systems to better incorporate social and behavioral determinants of health. Some of these determinants have already been incorporated into Meaningful Use Stages 1 and 2 to some extent. Stage 1 includes the collection of information on a patient's preferred language, gender, race, ethnicity, and

<sup>&</sup>lt;sup>4</sup> Personal communication, G. Hirpcsak, Colombia University, October 21, 2013.

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smoking status (HHS and CMS, 2010). CMS opted to use the Office of Management and Budget's (OMB's) five categories for race and two categories for ethnicity. An optional Stage 1 menu objective for hospitals was included to collect advance directives for patients ages 65 years and older.

The CMS Final Rule for Meaningful Use Stage 2, maintained the social determinants of health from Stage 1, but gender was changed to sex so that it aligned with vital statistics reporting and family health history was added as a menu objective (HHS, 2012). Furthermore, the summary of care record for patients who are transitioned or referred to another provider or care setting was required to include functional status, including activities of daily living and cognitive and disability status, if the provider knows it (i.e., if it is already recorded in the EHR). It was decided not to mandate the collection of disability status as a demographic variable because of the data collection burden and the lack of an agreed-upon definition. Gender identity and sexual orientation were considered but not included because of lack of consensus in public comments on whether doing so would be useful, the degree of sensitivity of the information, and how it would be recorded.

As of December 2013, the Meaningful Use Workgroup was developing recommendations for Stage 3. An August 2013 draft included items such as functional status with activities of daily living, relevant social and financial information, and relevant environmental factors affecting the patient's health; and the draft included the patient submission of information such as functional status (CPeH, 2013). At its August meeting, the HIT Policy Committee requested a change in emphasis so that all objectives included in the Meaningful Use Stage 3 definition were clearly linked to concrete health outcomes that were aligned with the national priorities. A new framework was created, and the workgroup was scheduled to present its recommendations to the HIT Policy Committee in March 2014 (Meaningful Use Workgroup, 2013).

### CHARGE TO THE COMMITTEE

With the National Institutes of Health at the helm, a collaboration among the Association of State and Territorial Health Officials, Blue Shield of California Foundation, California HealthCare Foundation, Centers for Disease Control and Prevention, CMS, The Lisa and John Pritzker Family Fund, the Robert Wood Johnson Foundation, and the Substance Abuse and Mental Health Services Administration was formed. Together, they requested that the IOM convene a committee of experts "to identify domains and measures that capture the social determinants of health to inform the development of recommendations for Stage 3 meaningful use of electronic health records (EHRs)." A 13-member committee was selected to address the charge. The committee comprised experts in the fields of social

determinants of health, health information technology, behavioral and psychological issues, and measurement. (See Appendix B for the biographical sketches of the committee members.)

This study is being conducted in two phases. Box 1-4 contains the complete statement of task for this study.

### COMMITTEE'S APPROACH TO ITS TASK

To meet its charge, the committee first established the rationale for adding social and behavioral domains into EHRs and considered how EHRs may assist providers in their decision making in a way that will result in improved health outcomes for their patients, regardless of Meaningful Use adoption and implementation. The committee held two information-gathering meetings in order to clarify its statement of task; learn about meaningful use objectives; and hear from other experts in the field, stakeholders, and the public on domains that the committee should consider. (See the meeting agendas in Appendix A.) After each information-gathering meeting, the committee met in closed session for discussion and deliberation.

Before the first meeting and throughout the study process, the committee reviewed relevant literature. Its formal review of the literature focused on identifying peer-reviewed, published literature, reports from governmental agencies, and other IOM reports that were germane to the statement of task. The committee used the Ovid Embase, Ovid Medline, and Web of Science search engines, setting limits and using in its search specific medical subject headings terms in their search pertinent to components of social and behavioral determinants of health. Given the vast literature on the range of social and behavioral determinants of health, systematic reviews were used when possible. The committee prioritized U.S. Preventive Services Task Force guidelines, as well as the Cochrane Database of Systematic Reviews.

For this study, the committee uses the term "candidate" to refer to the "core" domains (the third item of the Statement of Task) because the specific task for the Phase 1 report was to identify domains that should be considered by ONC for Stage 3 Meaningful Use. In this context the core domains are those that are "candidates" for being selected for Meaningful Use. The committee erred on the side of inclusion for its Phase 1 report while also trying to limit the number of candidate domains. Consequently, the committee expects to further winnow the list of candidate domains to a smaller number of recommended "core" domains in the Phase 2 report. Throughout the study, the term "domain" refers to determinants of health that could include health conditions that, in turn, influence other health outcomes. The committee also established the following working definitions for "domains," "measures," "data sources," and "EHRs": (1) the "domain" is the definition of the conceptual variable, (2) the "measure" is

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### BOX 1-4 Statement of Task

The Institute of Medicine will convene a committee to identify domains and measures that capture the social determinants of health to inform the development of recommendations for Stage 3 meaningful use of electronic health records (EHRs). The committee's work will be conducted in two phases and will produce two products. As part of its work, the committee will:

### Phase 1 (accomplished in this report)

- 1. Identify specific domains to be considered by the Office of the National Coordinator,
- 2. Specify criteria that should be used in deciding which domains should be included,
- 3. Identify core social and behavioral domains to be included in all EHRs, and
- Identify any domains that should be included for specific populations or settings defined by age, socioeconomic status, race/ethnicity, disease, or other characteristics.

A brief Phase 1 report will be produced and submitted to the sponsors by the end of March 2014.

### Phase 2 (to be addressed in a forthcoming report)

The committee will consider the following questions:

- 1. What specific measures under each domain specified in Phase 1 should be included in EHRs? The committee will examine both data elements and mechanisms for data collection.
- 2. What are the obstacles to adding these measures to the EHR and how can these obstacles be overcome?
- 3. What are the possibilities for linking EHRs to public health departments, social service agencies, or other relevant non-health care organizations? Identify case studies, if possible, of where this has been done and how issues of privacy have been addressed.

A final report that includes the Phase 1 report and addresses the Phase 2 questions will be the final product.

The committee will make recommendations where appropriate.

the specific instrument through which the domain is assessed or operationalized, (3) the "data source" is where the measure can be obtained, and (4) "EHRs" are collections of electronic data stored and used by health care providers to manage patients' health. For the purposes of this study, the committee employed a definition on social and behavioral determinants of

#### CAPTURING SOCIAL AND BEHAVIORAL DOMAINS IN EHRs

#### BOX 1-5 Social and Behavioral Determinants of Health Definition

"The term 'behavioral' refers to overt actions; to underlying psychological processes such as cognition, emotion, temperament, and motivation; and to bio-behavioral interactions. The term 'social' encompasses sociocultural, socio-economic, and socio-demographic status; biosocial interactions; and the various levels of social context from small groups to complex cultural systems and societal influences" (Office of Behavioral and Social Science Research, 2010).

health used in the National Research Council's report *Proposed Revisions* to the Common Rule for the Protection of Human Subjects in the Behavioral and Social Sciences (NRC, 2014), noted above in Box 1-5.

The study was limited by the need to keep a very tight timeline for preparation and publication of this first report to provide ONC and CMS the opportunity to consider the committee's candidate domains as part of Meaningful Use Stage 3. The committee first met in September 2013 and wrote this first report after its two initial meetings. Guided by a review of existing conceptual frameworks, the committee first identified an outline of the full set of domains for committee review and then narrowed these to a smaller number of domains best suited for consideration for inclusion in EHRs using evidence-based criteria and consensus methods.

Finally, the identification of thresholds for each measure was determined to be outside the scope of work of the committee described in the statement of task that the sponsor agencies presented to the committee. CMS uses thresholds to set the bar for the reporting of measures to achieve certification. For example, to measure smoking status, Meaningful Use Stage 1 threshold is "more than 50 percent of all unique patients 13 years or older seen by the [eligible physician] have smoking status recorded as structured data" (CMS, 2010, p. 1).

## ORGANIZATION OF THE REPORT

This first report describes the committee's process of selection of candidate domains for consideration for inclusion in all EHRs, including the conceptual frameworks used, the discussion of possible domains, and the criteria considered in the selection of domains (Chapter 2) and how specific populations are addressed (Chapter 3). Chapter 3 also identifies the evidence used to establish a candidate set of domains that the committee agrees should be considered for inclusion in all EHRs. Appendix A includes INTRODUCTION

the meeting agendas and the committee members' biographies are available in Appendix B.

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# Selection of Domains for Consideration

Social and behavioral factors are widely recognized to be important determinants of health and disease. Health care providers and systems can more effectively influence the health of their patient population if they have information on these determinants. Unfortunately, such information is currently insufficiently captured in most electronic health records (EHRs) (Tai et al., 2012). According to the Institute of Medicine (IOM) Committee on Data Standards for Patient Safety the key capabilities of EHR system are for patient safety, health information and data, management of results, order entry and management, decision support, patient support, electronic communication and connectivity, administrative processes and reporting, and population health management (IOM, 2003). Although the inclusion of social and behavioral determinants of health data in the EHR will provide clinicians with useful information that will allow them to better care for and support their patients, such information is also vital for improving the public's health.

A National Institutes of Health (NIH) 2011 report titled *Identifying Core Behavioral and Psychosocial Data Elements for the Electronic Health Record* provided the committee with a helpful description of the goals of including social and behavioral health domains in EHRs and standardizing them to maximize harmonization across systems and populations. The NIH report suggested that harmonized screening and collection of data on behavioral and psychosocial health issues will facilitate

1. Brief interventions in primary care and improved, patient-centered clinical decision making;

- 2. Shared decision making, goal setting, and action planning with increased engagement of patients, families, and care teams;
- 3. Improved patient education on risks associated with health behaviors and benefits of behavior change;
- 4. Patient population management for clinics, accountable care organizations (ACOs), and similar groups;
- 5. Meaningful use of EHR data, quality of care, and follow-up in primary care medical homes; and
- 6. Research that integrates data elements common to health behavior with biometric data, health care utilization, and clinical outcomes in EHRs (NIH, 2011).

This IOM committee agreed to add a seventh goal to NIH's list, which would be a population health and public health goal.

## FRAMEWORKS FOR DOMAIN SELECTION

In deciding which social and behavioral domains to consider for inclusion in EHRs, the committee identified and applied several frameworks that capture the range of health determinants, and using the criteria described below narrowed the list to a candidate set best suited for inclusion in all EHRs throughout the life course.

Several conceptual frameworks provide lists of key health determinants and indicate ways in which they are linked to disease onset and progression. These frameworks generally distinguish individual-level characteristics (such as biological factors, emotional and cognitive traits, and healthrelated behaviors) from features of the physical and social environmental contexts in which they emerge and operate. Although the frameworks vary with regard to the labeling of determinants of health and in organizing the determinants of health (Dahlgren and Whitehead, 1992; Evans and Stoddart, 1990; IOM, 2000a), they generally depict biological and physiological factors to be "downstream" determinants of health that may be modified through complex pathways shaped by "upstream" determinants, such as governmental or institutional policies and community-based conditions and interventions.

The committee reviewed a number of existing conceptual frameworks and selected three that appeared to be best suited for the committee's use in that they captured a range of determinants occurring at different levels along the continuum from upstream to downstream that affect morbidity, mortality, functional status, and quality of life. The multilevel model of Kaplan et al. (2000) bridges various levels of explanation and intervention, bringing together theory and empirical work that link observations of causal influence and mechanisms at a high level overview (see Figure 2-1). SELECTION OF DOMAINS FOR CONSIDERATION

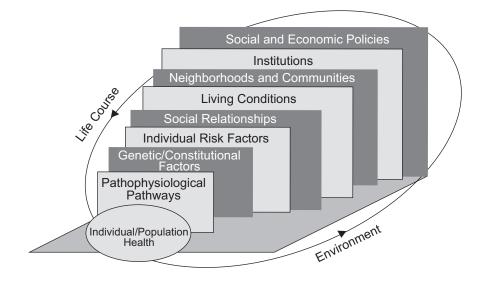
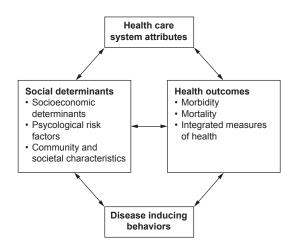


FIGURE 2-1 Multilevel approach to epidemiology, 2000. The approach of Kaplan et al. (2000) attempts to bridge various levels of explanation and intervention, bringing together theory and empirical work that link observations of causal influence and mechanism at multiple levels. SOURCE: IOM, 2000a.

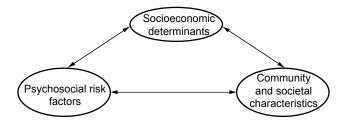
The public health models of the social determinants of health of Ansari et al. (2003) provide more specificity about the specific determinants that operate at each of these levels (see Figures 2-2 and 2-3). Finally, Figure 2-4, the MacArthur Research Network on Socioeconomic Status and Health's model moves beyond identifying determinants at various levels to positing some of the interrelationships among them (Adler and Stewart, 2010).

The committee used the model of Kaplan et al. (2000) in conjunction with the models of Ansari et al. (2003) to establish an overall framework and cross-checked the categories in the combined model with categories suggested by the MacArthur Research Network. Each framework addresses social and behavioral determinants of health from a distinct yet overlapping perspective. Although the public health model put forth by Ansari et al. (2003) is primarily anchored by the framework of Kaplan et al. (2000), it helps to explain why it is important to collect information about social determinants of health by illustrating that social determinants affect health in multiple ways: directly, through disease-inducing behaviors, and through the interactions that occur within the health system that people use. The



**FIGURE 2-2** Categorizations of social determinants of health. The approach to Ansari et al. (2003) illustrates how social determinants of health are usually put into four categories (social determinants, health care system attributes, health outcomes, and disease inducing behaviors) and the relationship among them.

SOURCE: Reprinted with kind permission from Springer Science + Business Media: Soz Präventivmed, 2003, Ansari et al., Figure 1.



**FIGURE 2-3** The public health model of social determinants of health. Approach of Ansari et al. (2003) used to diagram the interrelationship of the components of social determinants (socioeconomics, community and societal characteristics, and psychosocial risk factors) by use of a public health model of the social determinants of health.

SOURCE: Reprinted with kind permission from Springer Science + Business Media: Soz Präventivmed, 2003, Ansari et al., Figure 2. SELECTION OF DOMAINS FOR CONSIDERATION

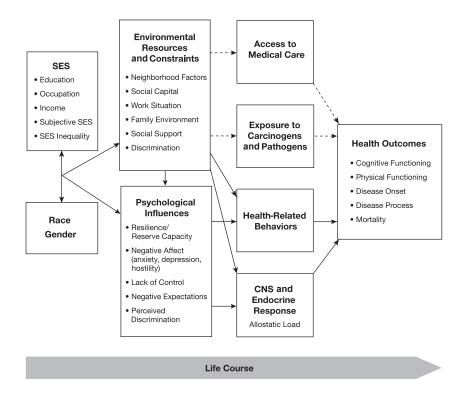


FIGURE 2-4 Pathways linking socioeconomic status and health. The solid lines indicate the pathways studied by the MacArthur Research Network on Socioeconomic Status and Health, and the dashed lines indicate pathways of importance that the network did not study.

NOTE: CNS = central nervous system; SES = socioeconomic status. SOURCE: Adler and Stewart, 2010, Figure 3.

outcomes that the model aims to explain are integrative measures of health that take into account disability. Although the MacArthur Research Network model focuses on those determinants associated with socioeconomic status, it comes up with a similar set of pathways to health involving access to care, health behaviors, exposure to toxins and pathogens, and responses to stressors.

The committee noted the strong linkage of health behaviors with a wide range of health outcomes. Numerous IOM reports have discussed the impact of behaviors at various times during the course of one's life span and stage of development, and strategies for modifying behaviors to

#### CAPTURING SOCIAL AND BEHAVIORAL DOMAINS IN EHRS

improve the health of specific populations (IOM, 2000a,b, 2005a,b, 2010). However, the committee was also keenly aware that the development and maintenance of health-damaging as well as health-promoting behaviors are affected by social and contextual factors. For example, changes in smoking behavior have occurred not only as a result of research findings on the harms of tobacco, but also as a result of policy changes affecting the cost of cigarettes, encouragement by health care providers to quit smoking, media campaigns, the existence of smoke-free environments, and changing social norms.

# SOCIAL AND BEHAVIORAL HEALTH DOMAINS

This section outlines the full set of domains that the committee reviewed as an initial step in identifying the set of candidate domains to be considered for inclusion in EHRs. Although most domains suggested for possible inclusion operated as a distal or a fundamental (in the terminology of Link and Phelan [1995]) cause of health, a few (e.g., depression) are both a health outcome that is affected by more upstream factors and a contributor to the etiology and course of other diseases (e.g., cardiovascular disease).

The majority of domains that the committee reviewed involve patientreported variables. In addition, the committee identified some domains related to neighborhoods and communities that patients themselves would not be likely to know but that are potentially geocodable. If the EHR contains information on the geographic location where an individual lives or works (e.g., a zip code or census block), this information can be linked to other databases to determine environmental conditions, such as air pollution or the availability of sidewalks, public transportation, and healthy food options.

At this first stage, the committee simply listed a wide array of potential domains for later evaluation. Table 2-1 lists all the potential domains that the committee evaluated. The committee agreed on the importance of the standardization of data collection and the need for this standardization to be accepted across geographical levels—federal, state, and community. Standardization needs to occur across agencies, including public health departments, medical settings, and health care organizations. In the long run, with the standardization of information and data linkages, fewer burdens will be placed on the health care community because some data will only need to be collected once (e.g., the patient's place of birth, the level of education of the patients' parents, the parents' medical history, and the patient's history).

# CRITERIA TO BE USED FOR DOMAIN SELECTION

Having adopted frameworks for identifying the social and behavioral determinants of health and reviewed the goals for inclusion of such domains in EHRs, the committee then established the key criteria that it would use in its Phase 1 and Phase 2 reports. Its deliberations were informed by the 2013 IOM report *Toward Quality Measures for Population Health and the Leading Health Indicators* (IOM, 2013).

The committee decided to use the following criteria to give domains high priority for inclusion in EHRs:

- 1. Strength of the evidence of the association of the domain with health.<sup>1</sup>
- 2. Usefulness of the domain as measured for
  - a. The individual patient for decision making between the clinician and patient for management and treatment;<sup>2</sup>
  - b. The population to describe and monitor population health and make health care–related policy decisions that affect the population cared for by the particular health system or as a whole; and
  - c. Research to conduct clinical and population health research to learn about the causes of health, the predictors of outcomes of care, and the impact of interventions at multiple levels.
- 3. Availability and standard representation of a reliable and valid measure(s) of the domain.
- 4. Feasibility, that is, whether a burden is placed on the patient and the clinician and the administrative time and cost of interfaces and storage.
- 5. Sensitivity, that is, if patient discomfort regarding revealing personal information is high and there are increased legal or privacy risks.
- 6. Accessibility of data from another source (as shown in Table 2-2, information from external sources may be accessible to meet the needs of patient care, population health, and research; if so, the domains would have less priority for inclusion in the EHR).

<sup>&</sup>lt;sup>1</sup> The committee supports the concept of the World Health Organization's definition of health being a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity. This definition was not originally included in the committee's Phase 1 report.

<sup>&</sup>lt;sup>2</sup> After publication of the Phase 1 report, edits were made to criteria 2.a., to clarify that decision making is between a clinician and a patient, and to criteria 5, to clarify that sensitivity includes legal risk.

I. Individual Factors		II. Individual–Level Social Relationships and Living Conditions	III. Neighborhoods/Communities
Sociodemographics Sexual Orientation Gender Identity Racial Identity Ethnic Identity Country of Origin/Migration History Language Education Cocupation/Employment Financial Resource Strain Food and housing insecurity Parental Level of Education Type of Insurance	Behavioral Dietary Patterns Activity Sedentary behavior Physical activity Sleep Substance Abuse Tobacco use and exposure Alcohol use Abuse of other substances Sexual Practices Exposure to Firearms Risk-Taking Behavior Distractive driving Helmet use Seat belt use	Social Engagement Marital Status/Family Structure Religious Involvement Civic, Sports, and Community Involvement Social Isolation Social Isolation Social Connections Instrumental Support Emotional Support Emotional Support Housing Stability and Safety	Compositional Characteristics Socioeconomic and Racial/Ethnic Characteristics Contextual Characteristics Air Pollution Allergens Other Hazardous Exposures Land Use, Urban Design, Walkability Nutritious Food Options Public Transportation, Parks, Open Spaces Health Care and Social Services Educational and Job Opportunities Safety/Violence Social Organization/Collective
		Work Conditions	Efficacy

TABLE 2-1 All Domains Committee Considered

36

LITERACY/HEALTH LITERACY	1 119101 ) 01 111101 CC1 411011
	Military Service
nger	Stress
Depression	
	Social Norms/Culture-health
Hopelessness	decision making
Psychological Assets	
Optimism	
Coping	
Control	
Conscientiousness	
Self-efficacy	
Positive affect	
Altruism/life satisfaction	
Patient empowerment/	
activation/engagement	
Cognitive Function in	
Later Life	
NOTE: The domains that are highlighted in gray shading note the committee's candidate set of domains best suited for inclusion in all electronic health records. The final list included in Chapter 3 indicates the committee's final phrasing of the domain title, which	NOTE: The domains that are highlighted in gray shading note the committee's candidate set of domains best suited for inclusion in all electronic health records. The final list included in Chapter 3 indicates the committee's final phrasing of the domain title, which

in some cases, folded two or more domains (listed in the table) into one domain. The original publication in Phase 1 had several editorial errors regarding the shading of the candidate set of domains and the labeling of domains/subdomains. The report has been

updated to correct the errors.

#### CAPTURING SOCIAL AND BEHAVIORAL DOMAINS IN EHRS

Data Source	Purpose	Example
Electronic health record (EHR)	<ul> <li>Captures data during course of care</li> <li>Provides data useful for decision making in the health system</li> <li>Provides a legal record of care</li> </ul>	• Domains and measures selected by committee
Personal journal/personal health record	<ul> <li>Captures information during life/work activities</li> <li>Allows the individual to record information</li> <li>Allows the appropriate information to be summarized in an EHR</li> </ul>	• Personal activity tracking log (i.e., Fitbit)
Domain-specific measurement instruments	<ul> <li>Assesses state or progression</li> <li>Allows the appropriate information to be summarized in an EHR</li> </ul>	• Health-related quality of life
Community datasets	<ul><li>Analysis of population samples</li><li>Analysis of patterns and trends</li></ul>	Community resources
National surveys	<ul> <li>Analysis of population samples</li> <li>Analysis of patterns and trends</li> </ul>	• Health interview survey

**TABLE 2-2** Health Information Surveys and Technologies

Table 2-2 provides a brief summary of the purposes of the EHR along with the purpose of data from other data sources to inform thinking about what is needed in the EHR and if linkages to other surveys or electronic storage of health information have potential use.

After the committee's first meeting, an expert consensus process was used so that the committee could promptly complete its first task: to identify a set of candidate domains for consideration for inclusion in all EHRs. Each committee member drafted write-ups on domains relevant to her or his areas of expertise.

Each committee member voted for her or his top ten priorities for consideration on the basis of the evidence provided by fellow committee members and the committee's review of the strength of association of the domain with health and the usefulness of the domain for the treatment of

#### SELECTION OF DOMAINS FOR CONSIDERATION

individual patient, population health, and research—the first two criteria listed above. The committee strove to err on the side of inclusion while also trying to limit the number of candidate domains. To further the committee's work in its subsequent report, criteria 3–6 will be applied. The Phase 2 report will likely produce a smaller set of recommended domains once all of the criteria have been applied.

The results of this first pass at a systematic scan of the evidence were summarized for a full committee discussion at its second meeting. The domains that received the most votes were discussed first. However, the committee did not feel that they could prioritize domains based on this vote without further application of the full criteria. Further, following the vote, some domains were aggregated and others were demoted because they had less compelling evidence of utility in the EHR. After a discussion of the full list of domains, unanimous agreement was reached on a candidate set of 17 domains.

Feasibility was not one of the criteria applied in this Phase 1 report, because existing measures had not been compiled for this Phase 1 report. The committee did discuss feasibility in the context of variables included under geocoding because some of those variables are not consistently defined and measured in current datasets and would require costly and time-intensive efforts to develop linkages to individual EHRs. The committee debated whether it was better to consider each variable as a domain or to treat the domain of "geocoding" as a single category, of which specific measures (e.g., the composition of a neighborhood or community by socioeconomic status or race/ethnicity and the level of air pollution and density of housing in a neighborhood or community) could be linked on the basis of a patient's home address. The first two examples, described later in the text, have the strongest evidence base, but other measures have potential uses as evidence gathers over time.

In sum, the committee, motivated by the value of including social and behavioral data in EHRs and informed by the various goals for doing so, developed a set of domains based on conceptual frameworks on the determinants of health. The results of that process are described in Chapter 3.

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# Identified Candidate Domains

As part of the committee's statement of task, identification of domains relevant for all individuals and specific populations was central to its deliberations. After it discussed all of the domains listed in Table 2-1, the committee recognized that demographic characteristics such as age and gender can be used to identify specific population groups in which candidate domains are especially relevant or in which a specific type of measure of a given domain may be warranted, or in which a domain may be particularly important. For example, if the patient is a child, education level does not yet exist, but capturing the education level of the child's parents is relevant to the child's health. Further, the use of nicotine and misuse of alcohol and prescription drugs are especially relevant to adolescents because they are of an age that makes them vulnerable to developing addictions. Additionally, exposure to violence occurring at a young age will also be more harmful, as the adverse effects accrue the earlier and continual that the child is exposed to violence. Women and adolescent girls are also at heightened risk for exposure to interpersonal violence. Lastly, patient willingness to provide information that they consider private, embarrassing, or that is illegal is a challenge to collecting accurate data. These examples highlight the challenge of capturing data of a sensitive nature, which will be explored further in the committee's second report. The following section describes the justification for the use of the life course approach that guided the committee's deliberations. While the committee did not identify any specific populations or settings for selected candidate domains, measures for these domains will be identified in its Phase 2 report and these measures may be tailored to specific populations, as guided by use of the life course perspective.

#### CAPTURING SOCIAL AND BEHAVIORAL DOMAINS IN EHRS

#### LIFE COURSE PERSPECTIVE

The life course perspective recognizes the complexity of health and development, and provides a lens through which early experiences and exposures can be linked with outcomes later in life (Kuh et al., 2003). The life course is characterized by events and specific transitions that can be thought of as forming trajectories (Elder, 2000) as social roles change from childhood (e.g., daughter, student) to adulthood (e.g., a pregnant woman, parent, worker) and older life (e.g., grandparent, retiree). Boys and girls enter school, adolescents graduate from high school, young adults live independently, adults marry, women have children, and elders retire. The concept of life course perspective is often equated with life span development (Alwin, 2012), which views human development, socialization, and adaptation as lifelong processes of continuity and change.

# Gender

Although biological differences between males and females have implications for their health, gender-based differences in health have social origins (Bird and Rieker, 1999). Across the life course, females experience unique health challenges, such as breast, ovarian, and cervical cancer; pregnancy; breastfeeding; and postpartum depression. Females have greater exposures to risks, such as violence from her intimate partner, and higher rates of some diseases such as depression and auto-immune diseases (IOM, 2010b). In contrast, males are uniquely prone to prostate and testicular cancer, have higher age-adjusted rates of cardiovascular disease, have a higher risk of accidental injuries, and have higher rates of early mortality. Moreover, symptoms and the presentations of some common diseases differ for males and females, and their responses to different treatments also differ (IOM, 2010b).

Examination of health determinants from a gender-based lens provides a better understanding of individual as well as population health. Females experience a number of social conditions that have health effects. For example, women (and particularly single mothers) are disproportionately likely to live in poverty and still earn less per hour than do males in the same occupation (DeNavas-Walt et al., 2013; NPC, 2014). A lack of attention to problems related to gender-linked social factors may help explain why researchers have made less progress on reducing the incidence of diseases, such as depression and auto-immune diseases in women than on reducing the incidence of, for example, cardiovascular disease and HIV/AIDS in men (IOM, 2010b). This lack of attention may also explain the continued high rates of preterm birth and infant mortality in the United States and the

weak association between the provision of prenatal care and birth outcomes (NRC and IOM, 2013).

A gender-based life course perspective suggests that health inequities result from differences in protective and risk factors among groups of women over the course of their lives (Manton et al., 2008). These societal contexts shape the gender differences in opportunities such as employment, which in turn, affect differences in exposure to adverse occupational hazards, stress, and other negative health consequences (Bird and Rieker, 1999). Because of pervasive and ongoing differences in patterns of illness between males and females, special attention needs to be paid to the health effects of gender (Short et al., 2013).

## Race and Ethnicity

As with gender, race has sometimes been viewed as a biologically defined characteristic but is now seen predominantly as a socially constructed category. Some diseases are more prevalent in groups from given geographical areas (e.g., sickle cell anemia in individuals of African and Greek ancestry, Tay-Sachs disease in Ashkenazi Jews). However, several other diseases that were once attributed to genetic differences among groups have been shown to have little relationship to geographical lineage (Williams et al., 1994). For example, the fact that hypertension rates are higher among African Americans than among European Americans has been assumed to be the product of genetic differences between African Americans and whites. This view is contradicted by research showing that rates of hypertension are actually relatively lower (not higher, as expected) among groups with a greater concentration of African lineage, including individuals in Africa itself (Cooper et al., 1997).

The aspects of race and ethnicity that are most relevant to health are those related to social disadvantage. For example, African Americans who experience high rates of morbidity and early mortality than do any other groups have had a long history of discrimination and disadvantage. As a result, they are exposed to more health-damaging environments and have fewer social and economic resources (Williams et al., 1994). For many, but not all, diseases, racial and ethnic differences are substantially reduced or eliminated when the rates are adjusted for socioeconomic differences (Isaacs and Schroeder, 2004). This finding suggests that race and ethnicity are markers for other social determinants of health and may also play a synergistic role for some health outcomes. Although there is a tendency to think of gender and race as fixed characteristics of individuals, the boundaries of the categories are, in fact, somewhat blurry and a person's sense of identity may not match how he or she would be categorized from a more biological perspective.

#### CAPTURING SOCIAL AND BEHAVIORAL DOMAINS IN EHRS

## SOCIAL AND BEHAVIORAL FACTORS IN THE LIFE COURSE PERSPECTIVE

In health sciences, it is now well recognized that physical health and psychosocial health change in response to the dynamic and relational interactions among an individual, the environments that he or she encounters, and his or her behaviors. For example, the increasing life expectancy and decreasing rates of disability among elders over time can be attributed to the healthier childhoods of successive generations, marked by better nutrition, improved sanitation, and increasing educational attainment (Manton et al., 2008). These advances in public health have contributed to the fact that today in the United States malnutrition, contaminated drinking water, and infectious diseases are not substantive threats to child or adult health.

Although rates of morbidity and mortality from infectious diseases have plummeted, the burden of mental health disorders and chronic illnesses among older populations has increased dramatically (CDC, 2009; Freid et al., 2012). A growing body of scientific evidence supports the claim that many of these health illnesses and disorders develop over the life course. That is, the health of adults is related to their health as children.

Stimulated by a series of studies demonstrating how growth during fetal and early life relates to the risk of chronic conditions in adulthood, life course health science as a field has begun mapping the developmental mechanisms of health (Ben-Shlomo and Kuh, 2002; Lynch and Smith, 2005). It is now clear that the network of social and behavioral factors that influence health at one stage of life differs both qualitatively and quantitatively from the network of factors that influence health at other stages of life. Complex processes that span the life course integrate a wide array of social and behavioral influences by modifying gene expression, modulating physiological and behavioral functioning, and shaping health trajectories (Halfon and Hochstein, 2002; Kuh et al., 2003). As the multilevel and multidirectional complexities of disease causation become understood, health science is currently moving toward a more systems-oriented ontology.

Adverse or favorable environmental stimuli experienced in one phase of life can have profound effects on health much later in life. For example, environmental exposures to adverse experiences at sensitive developmental periods can penetrate the skin, changing gene regulation and body structures in ways that alter the risk of future disease (Forrest and Riley, 2004; Hertzman, 2012). This has especially been shown in children who are even more vulnerable to environmental exposures during the fetal, infant, and early childhood stages of life, when development occurs at such a rapid pace. For example, Barker's seminal work has demonstrated the link among fetal growth retardation, low birth weight, and adult coronary disease (Barker, 1993, 1994, 1995).

Childhood exposures to different types of abuse, family stressors, or household dysfunction, known as adverse childhood experiences, have been shown to directly increase the risk of psychiatric disorder and chronic diseases that emerge in adulthood (Felitti et al., 1998). The maltreatment of a child, such as sexual abuse and neglect, substantially increases the risk that the individual will have anxiety disorders, substance abuse, and major depressive disorders later as an adult (Forrest and Riley, 2004; Jumper, 1995). The experience of abuse and rejection of the parent–child relationship appear to alter the structures and functions of children's developing brains and the reactivity of the body to stress (McEwen, 2008; McEwen and Seeman, 1999). These may also produce epigenetic changes that later interact with environmental stimuli to produce adult disease (Cole et al., 2012). Census data have also revealed that the socioeconomic environment early in life is associated with several adult chronic diseases, including Alzheimer's disease (Moceri et al., 2001).

Risk behaviors often emerge and are molded during childhood and adolescence and are maintained during adulthood, and repeated harmful exposures have cumulative effects on health status. For example, the growing awareness that most adults began to smoke as adolescents, that smokers experience deleterious effects, and the recognition of the lethality of smoking have resulted in health policies designed to decrease smoking advertisements that focus on adolescents and increasing the sales tax on cigarettes. These public health strategies have been effective in decreasing the numbers of new youth smokers (Forrest and Riley, 2004).

The life course perspective provides a framework for understanding how an individual's health and environmental exposures are connected to the development of disorders, disabilities, and death (Halfon and Hochstein, 2002; Hertzman, 1999; Hertzman and Power, 2003). This perspective suggests that health is produced across the life course and that childhood is a critical developmental period in this course (Barker, 1993, 1994, 1995, 2001). Both men and women have unique person–environment interactions at each stage of development (Forrest, 2005), and some of these can have profound effects on future health.

#### DOMAINS

The following section details the candidate set of 17 domains that the committee concluded is best suited for consideration for inclusion in all electronic health records (EHRs). The identification of these domains followed a consensus process, where the committee voted on their preferred top 10 domains, following a review of two identified criteria: (1) the strength of the evidence of the domain's association with health and (2) the usefulness of knowledge of the status of or information about that

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domain in (a) the treatment of an individual patient, (b) for the development of interventions or health-related policy decisions that could affect population health, and (c) for the performance of clinical and public health research. Research uses exist for every domain. Furthermore, the committee identifies examples of specifically relevant research needs, when applicable, throughout the text below. The set of 17 domains described in this chapter are not intended to serve as a final list of the committee's recommendations. The committee identified these 17 as strong candidates for consideration of inclusion in EHRs. The committee's Phase 2 report will detail the application of the full list of criteria to this set of candidate domains. A smaller set of recommended domains will likely result once that process is complete. *The domains that follow are not listed in order of priority, but instead are organized by the committee's initial outline, which ordered domains in terms of the types of data that they represented.* 

## Sociodemographic Domains

Sexual orientation Race and ethnicity Country of origin/U.S. born or non-U.S. born Education Employment Financial resource strain: Food and housing insecurity

## **Psychological Domains**

Health literacy Stress Negative mood and affect: Depression and anxiety Psychological assets: Conscientiousness, patient engagement/activation,<sup>1</sup> optimism, and self-efficacy

# **Behavioral Domains**

Dietary patterns Physical activity Tobacco use and exposure<sup>2</sup> Alcohol use

# Individual-Level Social Relationships and Living Conditions Domains

Social connections and social isolation Exposure to violence

<sup>&</sup>lt;sup>1</sup> The original publication in Phase 1 had several editorial errors in the labeling of domains/ subdomains. The report has been updated to correct the errors.

<sup>&</sup>lt;sup>2</sup> The Phase 1 report originally identified the domain as "nicotine use and exposure" but subsequently changed the domain to "tobacco use and exposure."

# Neighborhoods and Communities<sup>3</sup>

Neighborhood and community compositional characteristics

# Sexual Orientation

Sexual orientation is an amalgam of three concepts: sexual behavior, sexual attraction, and sexual identity (IOM, 2011a). Sexual orientation is defined as having a persistent pattern of or tendency to experience romantic desires or sexual desires for, and relationships with, people of the same sex, the other sex, or both sexes (IOM, 2011a). Meaningful Use Stage 2 regulations considered but did not include the collection of lesbian, gay, bisexual, and transgender (LGBT) data, as there was concern over the lack of consensus on definitions, and on the standards for structured data entry for gender identity and sexual orientation. However, numerous federally funded surveys include measures for LGBT individuals (IOM, 2011a).

Although gays and lesbians have in common a minority status in terms of sexual orientation, the health issues of gays and lesbians are different from each other. Most notably, although men who have sex with men are at higher risk for HIV/AIDS than heterosexual men, lesbians are at lower risk for HIV/AIDS than heterosexual women.

#### Evidence of Association with Health

Compared with heterosexuals, gays and lesbians have higher smoking rates (Tang et al., 2004), and lesbians, gays, and bisexuals are at greater risk for alcohol and drug use disorders (Green and Feinstein, 2012). Men who have sex with men are at greater risk for mental health problems (CDC, 2010a) and for suicides (CDC, 2010c). Further, men who have sex with men continue to be disproportionately affected by HIV and sexually transmitted infections (Rhodes et al., 2011). Lesbians might experience higher levels of breast cancer risk than heterosexual women, but more research is needed to identify if the risk is due to not bearing children or other risks factors, such as alcohol consumption or being overweight (IOM, 1999).

A multistate study of students in grades 9 to 12 found a higher prevalence of risk behaviors among gay and lesbian students than heterosexual students in the areas of violence, attempted suicide, tobacco use, alcohol use, drug use, sexual behaviors, and weight management (Kann et al., 2011). LGBT youth may be especially at risk if they perceive others as being

<sup>&</sup>lt;sup>3</sup> The original publication in Phase 1 had several editorial errors in the labeling of domains/ subdomains. The report has been updated to correct the errors.

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unsupportive. Among young adult LGBT individuals, those who reported receiving little support from their families as they came out had 5.6 times the amount of suicidal ideation, 8.4 times the amount of suicide attempts, almost 6 times the amount of serious depression, and significant increases in illegal drug use and unprotected sex compared to their peers who had supportive families (Ryan et al., 2009). A recent National Academy of Sciences report indicated that LGBT youth also experience a higher risk of being "thrown away" by their families and thus are more likely to experience homelessness (IOM and NRC, 2013a). LGBT homeless youth are at greater risk of being sexually abused because they are more likely to be commercially sexually exploited than non-LGBT homeless youth.

### Usefulness

If individual health care providers have information about their patients' sexual orientation, they can be better equipped to diagnose and counsel them on conditions that may be transmitted through sexual contact and perform appropriate tests (Makadon, 2011). For example, the Fenway Health organization suggests that for sexually active gay men, pharyngeal and rectal swab samples should be taken for culture (Fenway Health, no date). Although lesbians, gays, and bisexuals do not necessarily require specialized substance abuse treatment programs (this is, programs different from those for heterosexuals), the recommendation to individualize substance treatment requires understanding the life circumstances of lesbians, gavs, and bisexual persons (Green and Feinstein, 2012). In addition, negative attitudes about homosexuality can make it difficult for LGBT individuals to be open about same sex behaviors, which leads to stress, limits social support, and negatively affects health (CDC, 2010b). The sensitive nature of discussing same sex behaviors may lead to a lack of openness with health care providers or disclosing sensitive information electronically. Additionally, health care providers may have inadequate training to treat LGBT populations in a culturally competent manner.

It is unknown whether the availability of information on sexual orientation would allow health systems to provide specialized services for members of the LGBT population that would result in better outcomes for this group. The Centers for Disease Control and Prevention (CDC) notes that homophobia, discrimination, and stigma are social determinants of health that affect an individual's physical health, the ability to obtain health services, the ability to receive quality health care services, and the likelihood of experiencing violence (CDC, 2010b).

It is widely noted that LGBT people have unique health experiences and needs (IOM, 2011a). The availability of information on an individuals' sexual orientation would allow researchers to obtain more specific

information on the experiences and needs of the members of the LGBT population, especially of specific subgroups of LGBT individuals, rather than all LGBT individuals as a single homogenous group, were adequately analyzed. To advance understanding of the health needs of all LGBT individuals, researchers need more demographic data on these populations, increased numbers of individuals who are members of sexual and gender groups to participate in research, and improved methods for the collection and analysis of data on the LGBT population.

## Race and Ethnicity

As described earlier, although "race and ethnicity can be an important statistical predictor of an individual's risk for health outcomes and access to care" (IOM, 2009, p. 16), race is the product of both social and biologic influences and carries a wide range of meanings (Cooper et al., 2003). It is through the lived experience of race that individuals experience biological and genetic health consequences and disparities (IOM, 2012). Health disparities associated with race emerge from racial variations in exposure or vulnerability to psychosocial, behavioral, or environmental risk factors and resources (Williams and Collins, 2001; Williams and Mohammed, 2009; Williams et al., 1994, 1997).

Both racial and ethnic data categories are social-political constructs (OMB, 2000); and ethnic background is a broad construct that takes into consideration religion, common history, and cultural tradition, and often a shared genetic heritage (Burchard et al., 2003). These different population groups are used for an array of analytical purposes and statistical reporting, including identification of disparities in health and health care and health care quality assessment (OMB, 2000).

Throughout the life course, health disparities by race and ethnicity are apparent from an early age. For example, birth outcomes differ between non-Latino black and white infants, as non-Latino black infants are more than twice as likely than white infants to die within the first year of life (MacDorman and Mathews, 2011). This immediate disparity is attributable to increases in low birth weights; preterm births; and preterm causes of death, such as sudden infant death syndrome, congenital malformations and unintentional injuries among non-Latino black infants. While this affects the life course and potential health of the infant, it is also a reflection on the entire life course of the mother, encompassing the racial and ethnic disparities and stress that she experienced before pregnancy (Lu et al., 2010).

### Evidence of Association with Health

Thousands of published studies document variations in physical and mental health among groups of people by race and ethnicity. People of color experience disparate outcomes across numerous health indicators compared with whites although these differ by indicator and group. The most consistent findings are for African Americans and Native Americans. For example, among cardiovascular and related chronic diseases, the incidence of heart failure has increased at a higher rate among younger black males, suggesting that management of associated hypertension and diabetes is needed to reduce these racial disparities (Husaini et al., 2011). Additionally, African Americans are more than three times more likely than whites to develop end-stage renal disease than are whites (U.S. Renal Data System, 2013). Furthermore, Native Americans are more than two times more likely to be diagnosed with diabetes, and the prevalence of associated comorbidities is 50 percent greater among Native Americans than among the general U.S. population (O'Connell et al., 2010). Health disparities are also seen between genders and place of birth.

For example, despite the lower incidence of breast cancer in the United States, African American women are more likely to have a poorer prognosis and higher mortality rate of this form of cancer than white women. African American women are also more likely to be diagnosed with late stage breast cancer and have a more aggressive form of breast cancer that is harder to treat (ACS CAN, 2009; NCI, 2009; Susan G. Komen, 2013). Latinos and Asians have higher rates of some diseases than do European Americans, but lower rates of others (Acevedo-Garcia and Bates, 2008; Acevedo-Garcia et al., 2005; Lara et al., 2005; Parker Frisbie et al., 2001). First-generation immigrants from most ethnic groups have better overall health outcomes and lower mortality than do U.S.-born whites or members of their same ethnic group who were born and raised in the United States (NRC, 2004a; Rumbaut and Weeks, 1996; Sanchez-Aleman et al., 2011).

In the realm of mental and behavioral health, Native American children and adolescents who experience multiple traumatic experiences may be at a particularly high risk for developing posttraumatic stress disorders (Gnanadesikan et al., 2005). Low parental education levels appears to be a greater risk factor for substance abuse for white students than for Latino or African American students (Bachman et al., 2011). Another factor in the life course that disproportionately affects nonwhites is incarceration. As of 2008, African Americans and Latinos made up 58 percent of all prisoners, even though they comprise only a quarter of the U.S. population (NAACP, 2009–2014), with the majority being young men. Incarceration exposes individuals to higher levels of stress, disease, and violence. These exposures increase the risk of mortality compared with the risk for those who have not

been in prison. Incarceration alters the life course after prison and affects other opportunities along the life course such as stable employment (Pettit and Western, 2004) and may result in reduced earning potential (Western and Wildeman, 2009).

## Usefulness

If individual health care providers have information on their patients' racial and ethnic identity and ancestry, they can be better equipped to look for specific risks. Providers can better monitor patients and ensure that patients receive a high quality of care by appropriately hiring and training medical personnel (Baker et al., 2005; Hasnain-Wynia and Baker, 2006). Further, knowledge of a person's ancestry may facilitate providers in the testing, diagnosis, and treatment of disease when genetic factors are involved (Burchard et al., 2003) and can assist in identifying different risk-factor profiles. Knowledge of a patients' racial identity could assist providers in identifying the presence of psychosocial stressors disproportionally affecting certain racial groups, such as racial discrimination, which may negatively impact health outcomes.

If the health system has information on their populations' racial and ethnic composition, they will be better equipped to develop, apply, and use quality metrics stratified by race or ethnicity to improve clinical services, improve population health, and reduce health disparities (IOM, 2009). Such information will be helpful in guiding efforts to increase workforce diversity and improve culture competence to improve patient-centered care. Data on health needs and outcomes for specific racial and ethnic groups may also suggest ways that health systems can inform and bring about needed changes in the larger societal institutions and structures that determine exposure to health risks (Williams et al., 1994) to reduce racial inequalities through nonmedical social determinants of health (IOM, 2012). Residential segregation, for example, continues to be a major problem for people of color residing in low-income communities (IOM, 2012; Williams and Collin, 2001).

If researchers have information on individuals' racial and ethnic identity, in addition to data on the social factors that contribute to racial and ethnic differences in disease, they will be better equipped to establish the modifiable factors contributing to poorer outcomes among racial and ethnic groups, which will inform future interventions tailored to both individuals and population. In addition, improvements in health equity resulting from the Patient Protection and Affordable Care Act,<sup>4</sup> which has a number of

<sup>&</sup>lt;sup>4</sup> Public Law 111-148.

provisions that promote increased access to care (IOM, 2013c), need to be tracked to evaluate their impact on the health of affected populations.

#### Country of Origin/U.S. Born or Non-U.S. Born

Ethnic groups are largely defined by geographical origin or where they currently reside. The health of individuals residing in the United States is associated not only with the ethnic group with which they identify with but, as noted above, by how recently they came to the United States. Several markers are used to identify immigration status. Acculturation is a concept that captures the extent to which an individual identifies with and is guided by the norms, values, and practices of her or his own ethnic group or those of the prevailing U.S. culture. Acculturation is assumed to grow with increasing length of residency in the United States along with the individual's preferred language. Variables in clinical practice that might be related to acculturation include the number of years in the United States as well as the language that the individual prefers to use during the clinical encounter. Country of origin and migration status may also be related to health because of their association with immigration, refugee status, and documentation status which may reflect issues of access to health care and related issues, as well as health-related exposures in the country of origin.

#### Evidence of Association with Health

The United States has long been a country in which immigrants have formed an important segment of the overall population. Immigration is one of the three major contributors to demographic shifts in the United States with continued trends toward a net influx of people into the nation (Shrestha and Heisler, 2011). The associations relevant to health are potentially multiple and include several concepts, which follow.

Communication is essential for health and effective health care (see the Health Literacy section later in this chapter). Language, literacy, and numeracy may be of particular concern in providing effective care for immigrant groups. The association of acculturation with health is complex and varies by communities and conditions. In the health of the Latino population, for example, acculturation may be associated with either positive or negative health effects. In certain areas—dietary practices, birth outcomes, and substance abuse—evidence indicates that acculturation has a negative effect and that it is associated with worse behaviors, perceptions, or health outcomes. In others, the effect is mostly in the positive direction, such as in use of the health system and self-perceptions of health (Lara et al., 2005). Smoking behavior among immigrants follows a complex pattern related both to their country of origin (and the smoking rates in those countries)

and sex to the degree of assimilation in the United States (Lara et al., 2005; Leung, 2013).

Protection of refugees is one of four primary reasons that the United States allows people to immigrate. The top 10 countries of origin for refugees are Afghanistan, Iraq, Somalia, the Democratic Republic of Congo, Myanmar, Colombia, Sudan, Vietnam, Eritrea, and China (CDC, 2012b). The United States remains 1 of the top 10 countries receiving these refugees. Refugees of all age groups are at risk for multiple health issues related to exposures to violence, toxins, nutritional deficiencies, infectious diseases, and poverty (IPC, 2010). Among refugees, rates of serious mental health issues may be 10 times higher than the rate for the general U.S. population (Fazel et al., 2005).

The CDC is responsible for preventing the transmission, introduction, and spread of communicable diseases into the United States; and it is also responsible for developing the guidelines, known as technical instructions, used in the overseas medical examinations conducted to identify other medical conditions and treatments that are required prior to entering the United States. The CDC recently reported on an electronic reporting system that collects health information on immigrants and refugees newly arriving in the United States (Lee et al., 2013). Refugee applicants rendered as inadmissible require a waiver for entry and are classified with a Class A medical condition. Applicants that are admissible but that may require treatment or follow-up for a health condition are allowed to enter the country and are classified with a Class B medical condition. Information in the Electronic Disease Notification System is used to notify the health departments of all 50 states and the District of Columbia about the arrival of these individuals into the United States. Furthermore, individuals entering the United States without documentation are at increased risk for poor health and poor health care access, and are likely not to be included in ongoing surveillance.

#### Usefulness

If individual health care providers have information on their patients' country of origin, identification of the patient's preferred language will likely ensue so that appropriate translator services may be provided. Knowledge about a patient's country of origin can improve the quality of care through better (1) communication that recognizes potential limitations in health literacy and the need for interpreters and culturally competent care (that is, understanding the role of acculturation as a facilitator or barrier to health promotion, (2) care for recent immigrants and refugees for conditions that require follow-up beyond the initial medical examination required for immigration, and (3) identification of and care for medical conditions related to exposures in the country of origin, particularly the identifica-

tion of and care for the mental health conditions among immigrants and refugees of all ages.

If the health system has information on their population's country of origin, they can ensure that they have appropriate staff needed for translation services and understanding different cultural approaches to health care.

## Education

Education is a widely used social measure that captures the knowledge and skills gained through education and the credentialing linked to the completion of various levels of schooling. Both the number of years of time formally spent in school and the highest degree earned thus have implications for health, as does the quality of the education. Education (level, highest degree, and quality) is consistently associated with other measures of socioeconomic status (SES). The nature of this relationship is complex but quite consistent and an important contributor to health disparities (Marmot et al., 2008). Education levels for women have been recognized to be one of the most significant contributors to health and prosperity in many countries (Hausmann et al., 2009). Although education may operate in part by affecting health literacy, the latter is a distinct domain that is discussed here. SES as a child is assessed by indicators such as parental education and occupation, whether the home was rented or owned during childhood, and the size and the quality of the home. In most studies, these indicators are assessed by retrospective assessment.

## Evidence of Association with Health

Beginning in the late 19th century and continuing into the 20th century, birth cohorts enjoyed progressively higher levels of education that have been associated with greater wealth, longer life expectancy, lower rates of chronic disease (such as cardiovascular diseases), and better health outcomes. Langa et al. (2008) illustrated with data from the U.S. Health and Retirement Study that lower educational levels explained most of the variance associated with the declines in cognitive impairment in older adults. These results confirm findings from an earlier paper by Manton et al. (2008) analyzing interviews in a survey of long-term care (Larson et al., 2013). These relatively recent papers add to an abundance of data showing that educational levels are associated with health, health outcomes, the health care received, and health habits.

The link between education and health begins at an early age and continues throughout the life span. Children who do not receive a strong education at an early age will likely face poorer health as adults (Commission to Build a Healthier America, 2009). Other data support a relationship

between education level and the incidence of diabetes mellitus, as well as an association of education with alcohol consumption, physical activity, weight, sleep habits, and prevalence of chronic conditions, among other aspects of health and health care (Feinstein, 1993). These associations have been confirmed repeatedly for health outcomes and health habits over the ensuing decades and establish education level as an important determinant of health, well-being, and life expectancy (IOM, 2001).

Education level, a core component of SES, has long helped predict life expectancy. Typically, higher education levels translate into a longer life span for people across all genders, races, and ethnicities. Changing social conditions can modify the associations among education, race and ethnicity, and health. Education attainment, along with socioeconomic indicators, such as wealth and income, are related to the gaps in life expectancy seen among the various U.S. populations. Although life expectancy has increased among those living in the United States, the rate of increase has not been the same across all populations. For example, a recent research study found that the largest disparity in life expectancy is seen between the highest educated (postgraduate degree) and least educated (less than 12 years of education) (Olshansky et al., 2012). The same study also found that despite increasing life expectancies for African Americans, Latinos, and whites with a high school education or more, whites longevity in the United States, with less than 12 years of education, have worsened since 1990.

Galobardes et al. (2004) reviewed 29 studies (prospective, casecontrolled, and case-sectional) linking SES indicators during childhood with mortality in adulthood, regardless of the SES level in adulthood. Among male adults studied, lower childhood SES was linked with an increased risk of mortality from chronic disease, such as coronary heart disease; stroke; respiratory disease; diabetes; cancers of the lung, liver, and stomach; and digestive system diseases. Among the same group of men, lower SES during childhood was also linked with a greater risk of mortality caused by alcohol related deaths, homicides, and accidental injuries (Galobardes et al., 2004). Another review of 49 observational studies (Pollitt et al., 2005) concluded that an increased risk of cardiovascular disease in adulthood was associated with increasing number of years (including childhood) spent in low-SES circumstances.

#### Usefulness

If individual health care providers have information on their patients' education level, a low level of educational attainment might help them recognize if a patient may not have the capacity to understand and adhere to recommended treatment. Further, the health care provider can determine if

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extra support is needed to assist patients in addressing areas in which they are advised to improve their health.

If the health system has information on their population's education levels, health care organizations could use data on individual and parental educational attainment to influence policy changes that protect health. Knowledge of resources for continuing education in the local area could be an important tool to encourage referrals to educational facilities, as critical risk factors associated with worse health outcomes are increasingly concentrated in lower socioeconomic groups and in populations with less education. The primary utility of measuring parental education in adult patients is for research. It is less informative for patient care.

### Employment

Individuals who are employed have a job or occupation, usually in the formal paid labor market (including self-employment). Employment is sometimes (but less often) considered to include work in the household or in the informal economy or labor market. One component of employment is whether or not one is working (or working for pay). A second component is the type of employment and the conditions that this implies, including exposure to health risks and hazards in the workplace, income, stress, and provision of health care insurance. In addition, employment and occupation are also centrally socially and psychologically linked to a person's identity and social position in an organization, community, or broader society.

## Evidence of Association with Health

A large literature base has documented the affects of being employed and of various physical and psychosocial exposures at work that affect health of working youth and adults. For example, studies have shown that unemployed persons report lower levels of psychological well-being, have a higher prevalence of unhealthy behaviors, and experience higher morbidity and mortality than employed individuals (Bartley and Ferrie, 2001; Voss et al., 2004). Perceived job insecurity is also an important predictor of poor health, and job loss has been found to have adverse health consequences, including increased morbidity and mortality not only from mental illness but also from cardiovascular disease (Bartley, 1988, 1996; Bartley and Ferrie, 2001; Burgard et al., 2007; Dupre et al., 2012; Gallo et al., 2004; Martikainen, 1998; Martikainen and Valkonen, 1996; Strully, 2009; Sullivan and von Wachter, 2009; Valkonen and Martikainen, 1996; Voss et al., 2004). Temporary employment or so-called flexible employment also have associations with adverse affect on health (Artazcoz et al., 2005; Benach et al., 2002, 2013; Virtanen et al., 2005a,b). Under the current

health care insurance system in the United States where insurance is tightly tied to employment, employment has obvious consequences for health care insurance for an individual's immediate family members and for their ability to access prescription drugs.

Finally, aspects of particular kinds of jobs have been linked to health outcomes. Numerous studies document health outcomes related to young age, shift work, exposure to toxins, and static or tiring work conditions (Lee and Krause, 2002; Solidaki et al., 2010; Stomberg et al., 2010; Tamosiunas et al., 2005; van der Windt et al., 2000). Different occupations carry varying risks for adverse health effects-for example, health care workers are at an increased risk for many infectious diseases, including hepatitis A virus, hepatitis B virus, hepatitis C virus, HIV, and Mycobacterium tuberculosis, among many others. Waste collectors are at risk for hepatitis A virus, hepatitis B virus, hepatitis C virus, and Helicobacter pylori, Brucella, and Toxoplasma gondii (Haagsma et al., 2012). Chronic exposure to occupational noise is strongly associated with increased rates of coronary heart disease and hypertension compared to those never exposed (Gan et al., 2011). Occupational exposure to adverse inhalable particles, such as crystalline silica (mineral dust), coal dust, or beryllium, increases the risk for several diseases including lung cancer, pulmonary tuberculosis, chronic obstructive pulmonary disease, and decreased lung function (Calvert et al., 2003; Carta et al., 1996; Kreiss et al., 2007). Extended work hours have been associated with greater fatigue, cardiovascular disease, and disability retirement (van der Hulst, 2003).

## Usefulness

If individual health care providers have information on their patients' employment status, it will be useful to the provider for establishment of a diagnosis (because of the importance of occupational exposures to many health outcomes) and identification of a treatment (because of the implications of employment for the patient's ability to comply with the recommended treatment). The experiences of job loss and being unemployed also have health consequences that may be relevant to provider understanding of the etiology and prescription of the appropriate treatment.

If the health system has information on their populations' employment status, they can characterize their patient populations on the basis of an important social dimension, which will be of utility in targeting patients to various programs. Systems serving populations with a large portion of unemployed individuals could, for example, consider instituting job skills training to enrich their own workforce. The Backyard Project, for example, located in Minneapolis, Minnesota, and headed by Allina Health, works in neighborhoods and addresses more than the immediate medical needs

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of the community to provide engagement within their neighborhoods and to help members of the community become involved in their own health outcomes (Allina Health, 2013). Descriptive data on trends in various health conditions over time and the variability in the clinical presentation of health conditions as a function of employment may be useful to public health agencies as they target various prevention efforts or screening programs, and in their efforts to inform economic policies as part of initiatives to include "health in all policies" (PHI, no date).

#### Financial Resource Strain: Food and Housing Insecurity

Financial resource strain encompasses both the subjective sense of strain as the result of economic difficulties and specific sources of strain, including employment insecurity, income insecurity, housing insecurity, and food insecurity. Financial resource strain does not only reflect the absence of sufficient resources but also may reflect the lack of availability of an individual's skills and knowledge needed to manage resources. Employment and income security indicates that adequate financial resources are available to the home and its residents and that the physical, psychological, and health risks associated with various aspects of work are stable. The stress that an individual may encounter due to worrying about current and future security may be as impactful as the conditions of scarcity themselves.

Various types of financial insecurity interact with one another. For example, housing insecurity (which takes many forms, including multiple moves, crowding, foreclosure, and homelessness) can get pitted against food insecurity as households may compromise housing standards to preserve money for food (IOM, 2013d). Some evidence also indicates that the development of certain skills may mitigate these challenges of financial resource strain. One study by Gundersen and Garasky (2012) reveals that households with greater financial management abilities are less likely to be food insecure even for those living in extreme poverty. Additionally, Caswell and Yaktine (IOM, 2013d) reported that basic training in food sourcing and food purchasing and preparation improves food choices and extends the purchasing power of the allocation from the Supplemental Nutrition Assistance Program (SNAP).

Financial resource strain is a characteristic of a household or family unit and not simply individual. The committee considered collection of income as a domain but found it to be a complex and sensitive measure.<sup>5</sup> Financial resource strain is also influenced by the characteristics of the com-

<sup>&</sup>lt;sup>5</sup> This sentence was added for clarity, but it was not included in the published version of the Phase 1 report.

munity, such as access to grocery stores, neighborhood housing stock, and crime rates (NRC, 2009).

## Evidence of Association with Health

Various types of financial insecurity have been linked to health problems, although the evidence is mixed. For example, although job insecurity was shown to have little impact on persistent inequalities in morbidity and cardiovascular risk factors (with the exception of depression), and despite steep gradients in perceived job insecurity among employed persons (Scott-Marshall and Tompa, 2011), the overall level of financial insecurity was found to be a variable that significantly explained a variety of inequalities, particularly among women, older workers, and minorities (Scott-Marshall, 2009). Financial insecurity appears to be mediated through stress, and may have greater consequences for men (Gaunt and Benjamin, 2007).

Housing insecurity is associated with poor health, nutrition deficiency, and developmental risk among young children (Cutts et al., 2011). For example, persistent household food insecurity (without hunger) was associated with a 22 percent greater odds for child obesity (odds ratio = 1.22, 95 percent confidence interval = 1.06 to 1.41) than that in households with persistent food security (p < 0.05) (Metallinos-Katsaras et al., 2012). Food insecurity in older adults is a clinically relevant problem resulting in harmful consequences on quality of life, physical health, mental health, and nutrition (Lee et al., 2010). Although food insecurity disproportionately affects men.

Cumulative stressors (housing insecurity, food insecurity, employment insecurity, costly medications, and financial strain that causes barriers to health care access) explored in a cross-sectional study of more than 1,500 patients arriving for care in emergency departments (EDs) were associated with an increase in prevalence of depressed mood, stress, self-rated poor health, smoking, and illicit drug use (Bisgaier and Rhodes, 2011). Additionally, another study found that individuals with unstable housing are less likely to be able to manage their diabetes, perhaps mediated by self-efficacy (Vijayaraghavan et al., 2011).

#### Usefulness

If individual health care providers have information on their patients' financial strain, it can influence the recommendations that they provide (i.e., if they know that their patient cannot afford to join a gym, they might instead recommend free options, such as hospital activity programs). Financial resource strain not only predicts downstream health

outcomes but also may be a factor in determining the effectiveness of an intervention or the increased risk of infectious disease (Sivapalasingam et al., 2009a,b).

If the health system has information on their populations' financial strain evidence indicates that community-level interventions, such as rental vouchers but not subsidized housing, may mitigate the effects of housing insecurity (Lindberg et al., 2010). However, as such interventions mostly take place outside of the health care delivery system, strong links with community partnerships are needed to link patient data with their needs and the available resources. For example, among low-income patients arriving at an ED of a hospital, 23.6 percent had housing instability and 42.7 percent were determined to have food insecurity; both of these led to differential access to care (Kushel et al., 2006), suggesting a need to identify interventions to address housing and food insecurity before hospital visits.

### Health Literacy

Health literacy is defined in the IOM report Health Literacy: A Prescription to End Confusion, as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (IOM, 2004, p. 20). Health literacy goes beyond the ability to read, requiring decision-making skills, listening, and analytical processing, as well as the ability to apply these skills to health situations. A person who functions adequately at home or work may have marginal or inadequate literacy in a health care environment. Low health literacy is not uniformly distributed in society with the prevalence of limited health literacy being the highest among patients who are older or members of racial and ethnic minority groups (IOM, 2011b). According to the National Assessment of Adult Literacy, "approximately 36 percent of adults in the U.S. have limited health literacy, 22 percent have basic health literacy, and 14 percent are below basic health literacy. An additional 5 percent of the population is not literate in English. Only 12 percent of the population has a proficient health literacy level" (Almader-Douglas, 2013; Kutner et al., 2006).

Numeracy refers to the ability to use basic probability and mathematical concepts (Peters et al., 2006) and, as with health literacy, is the degree to which individuals have the capacity to obtain, process, and understand the quantitative health information and services that they need to make appropriate health decisions. Even highly educated individuals (including physicians and other providers) can be innumerate (Peters et al., 2013).

### Evidence of Association with Health

The IOM report on health literacy reviewed the association of health literacy with health outcomes and concluded that although causal relationships between health literacy and health outcomes are limited and yet to be established, studies have found cumulative and consistent findings suggesting a causal connection (IOM, 2004). However, considerable evidence of associations between low health literacy and a range of health outcomes exists. For example, "people with low health literacy have a lower likelihood of getting flu shots, understanding medical labels and instructions, and a greater likelihood of taking medicines incorrectly compared with adults with higher health literacy" (Almader-Douglas, 2013). They are also less likely to use preventive care; are more likely to self-report poorer health status (IOM, 2004); and are more likely to use the emergency room for care, be hospitalized, have adverse disease outcomes, and have higher mortality rates (Baker et al., 1998, 2002; Berkman et al., 2004b; Schillinger et al., 2002). Low health literacy affects the ability to give informed consent and to participate in shared decision making. For chronic conditions requiring a high degree of self-management (e.g., diabetes, hypertension, asthma), low health literacy is associated with poor outcomes because of lower levels of understanding about the condition and lower rates of correct use of medication (Gazmararian et al., 2003; Pignone and DeWalt, 2006).

A systematic review of numeracy by Berkman et al. (2011) found insufficient evidence for causal associations among health literacy, ambulatory care, health care services, risk perception accuracy, and accurate interpretation of health information; but it did find that numeracy appeared to mediate some health disparities for specific health outcomes in patients with diabetes and HIV infection. A 2013 IOM workshop on numeracy noted that numeracy may be more highly correlated with health outcomes than health literacy, although possible ceiling effects on health literacy could have clouded the effects of health literacy (IOM, 2013a). That workshop summarized that for management of ongoing health problems (such as chronic conditions) proficiency in numeracy is necessary, yet only 13 percent of the U.S. population overall has such proficiency (IOM, 2013a).

### Usefulness

If individual health care providers have information on their patients' health literacy level, they will be able to know when to use tools with the potential to improve their care, targeting efforts toward providing their patients with greater understanding of medications, self-care, and shared decision making avoiding errors resulting from inadequate communication.

If the health system has information on their populations' health lit-

eracy, it may help them to best allocate resources to help individuals choose health plans and make health-related decisions (Peters et al., 2013). Ultimately, health plans should be able to effectively manage their populations' health, particularly chronic conditions, and avoid medical errors. Literacy and numeracy may mediate between health literacy and poor health outcomes for some populations (e.g., members of racial minority groups, people with limited education) and define additional health and health care vulnerabilities that have yet to be identified.

If researchers have information on individuals' health literacy linked to health outcomes, they will be better able to devise individual and systemsbased approaches to enhance understanding and develop more effective health care communication tools (NIH, 2013; PCORI, no date).

### Stress

Stress has been defined as a subjective state that arises when an individual recognizes a situation as threatening but dealing with the threat requires more resources than he or she has available. Stress has negative health consequences when it exceeds an individual's ability to cope, particularly when it is severe or chronic. The environmental exposures that trigger such perceptions are called stressors, which can be acute or chronic. Acute stressors are discrete, observable experiences with a relatively clear beginning and end, and include devastating traumatic experiences, such as being a victim of rape or a criminal attack, and acute life events, such as the death of a loved one or the loss of employment. Chronic stressors encompass those in major domains of life such as ongoing marital problems, financial difficulties, and problems at work, and more minor but recurring everyday hassles such as being stuck in traffic, having too many things to do, concerns about one's weight, and misplacing or losing things. The continuous wear and tear resulting from many chronic stressors may be cumulative and severe (McEwen and Seeman, 1999).

Not all experiences of stress are damaging to one's health. If a threat or demand can be averted or mastered, the experience may be tolerable or even positive (Shonkoff et al., 2009). However, long-term exposure to stressors that one cannot manage and that are out of the individual's control creates an allostatic load that increases a person's vulnerability to a range of health problems (Seeman et al., 2001). Failure to measure psychosocial stressors comprehensively has markedly understated the contribution of stressors to health (Thoits, 2010). The experience of acute and chronic stressors during the critical first years of life, known as early life adversity, can have enduring changes on brain development and responsiveness to other subsequent stressors in both animals and humans (Shonkoff et al., 2009).

Capturing the effects of stress on health requires assessment of the rel-

evant aspects of the psychosocial environment that tax or challenge adaptive capacities. Accordingly, stressors can arise in various arenas in which people operate (e.g., housing, occupational, financial, and neighborhood stressors) and in relation to the major roles or statuses that they assume (e.g., childhood, parental, and marital stressors). Members of racial/ethnic minority groups have an elevated risk of exposure to acute and chronic discrimination, higher levels of stress, and greater clustering of stressors (Sternthal et al., 2011).

### Evidence of Association with Health

A large and growing body of research links the experience of psychosocial stress to health. In addition to the physiological effects of toxic stress that increase an individual's risk for disease, individuals may also try to cope with these stressors through behaviors with negative health consequences (Adler and Stewart, 2010). Studies have shown that stressful life events can lead individuals to both internalize symptoms, causing health problems, and simultaneously externalize the response to stress through negative behaviors, such as substance abuse (King and Chassin, 2008).

Chronic levels of stress in individuals have been linked to many negative health outcomes, including high blood pressure, a greater susceptibility to infection, and the buildup of fat both in blood vessels and around the abdomen (Adler and Stewart, 2010). Increased levels of stress during pregnancy may have negative impacts on the fetus and may also adversely affect neonatal outcomes, in addition to having negative impacts on the cognitive and emotional development of the child (Bittner et al., 2011). Studies of early life adversity, such as emotional abuse, physical abuse, neglect, or severe punishment, have found that such adversity is associated with an increased risk of subsequent physical, mental, and cognitive disorders in childhood and adulthood (Shonkoff et al., 2009).

The physiological pathways by which psychosocial stressors can affect health include neuroendocrine activation and altered immune function, as well as the stimulation of lymphatic tissue in response to stress-induced behavioral coping mechanisms, such as increased smoking. The effects of stressors on the regulation of immune and inflammatory processes have the potential to influence a broad range of outcomes including depression, infections, autoimmune and coronary artery disease, and at least some cancers (e.g., virally mediated cancers) (Cohen et al., 2007).

Disease risk has also been linked to stressors encountered in specific life domains and by some subpopulations. Recent reviews of research conducted with populations from multiple racial groups in the United States, and elsewhere, document that experiences of discrimination have pervasive adverse effects on a broad range of subclinical disease processes and that

these experiences contribute to racial/ethnic disparities in health (Pascoe and Smart Richman, 2009; Williams and Mohammed, 2009). A recent meta-analysis found a modest association between work-related stress or insecurity and incident cardiovascular heart disease (Virtanen et al., 2013) and a recent review concluded that psychosocial stress at work predicts incident cardiovascular disease morbidity and mortality. The associations are clearer for men than for women (Backé et al., 2012).

### Usefulness

If individual health care providers have information on their patients' stress as part of the EHR, they can work with patients to ensure that they have support systems in place to help manage stress and to prevent it from becoming toxic (Adler and Stewart, 2010). For example, there are opportunities for preventive interventions during pregnancy to help ensure that levels of stress, depression, and anxiety are managed in pregnant women to prevent any negative birth impacts (Bittner et al., 2011).

Providers can refer patients to stress management programs and help them assess whether stress exposures are exacerbating other health problems. For some sources of toxic stress, like interpersonal violence, health care providers can be helpful to patients in developing the skills, resources, and support networks that they need to address the problem and provide critical social support (Coker et al., 2002; McCaw et al., 2002).

If the health system has information on the overall stress levels in their populations and the predominant stressors, they will be better equipped to help policy makers and communities identify (and, it is hoped diminish) environmental sources of stress and use subsequent data from the EHR to monitor the effectiveness of such efforts.

If researchers have information on the sources and/or levels of stress of patients linked to other data in the EHR, they will be able to (1) more precisely estimate the contribution of stress to disease onset and progression, (2) determine both the direct effects and synergistic effects of stress, other risk factors, and mediators, and (3) develop more targeted prevention and treatment interventions for stress (Park et al., 2001). For example, given findings from animal models on the epigenetic effects of stress exposure early in life (Meaney, 2001; Weaver et al., 2004), an expanded EHR could provide data that would allow tests for such effects in humans and advance the development of precision medicine.

### Negative Mood and Affect: Depression and Anxiety

Depression, anxiety, hopelessness, and anger/hostility are interrelated and can occur throughout the life course, from childhood to late in life.

Disorders of anxiety and depression are often comorbid and extreme feelings of hopelessness are signs of depression. Although some theorists posit a commonality among these measures of negative affectivity (Leiknes et al., 2010), most epidemiological analyses have not included more than one type of negative emotion and have rarely considered whether the effects are independent of positive emotions. This section will review depression and anxiety.

Depression and anxiety are commonly reported emotional problems, and they are highly related. In extreme forms, these are considered diseases themselves (clinical depression and anxiety disorder), but milder, subclinical levels of depression and anxiety are also important, in that they diminish quality of life and can increase the risk of other diseases, such as diabetes and cardiovascular disease. Thus, they are simultaneously health outcomes and determinants of health. Although the committee found depression and anxiety to be better suited for consideration for inclusion in EHRs, it also noted the contributions of anger and hostility and hopelessness to poorer health.

Depression is characterized by sadness and decreased interest in usually pleasurable activities, along with the feeling of worthlessness, fatigue, sleep problems, weight and appetite changes, and difficulties concentrating. For the diagnosis of major depression, the characteristics should last 2 weeks or more, interfere with daily functioning, and represent a change from usual characteristics. In children, depressed mood may manifest as irritable moods and weight changes, including the failure to make appropriate weight gains within their age group (APA, 2013).

Major depression is highly prevalent. According to the National Comorbidity Survey, approximately 20 percent of women and approximately 13 percent of men have a lifetime history of major depressive disorder, and approximately 25 percent of women and 18 percent of men have a history of any mood disorder (Kessler et al., 2005). Mood disorders are also common in adolescents, with a prevalence of approximately 15 percent (approximately 12 percent have major depression and approximately 3 percent are diagnosed with bipolar disorder) (Merikangas et al., 2010). For example, among postpartum women, 14 percent of 10,000 women delivering a live infant at an urban hospital were found to screen positive for depression (Wisner et al., 2013). Furthermore, major depression is the second leading cause of disability worldwide according to the Global Burden of Disease Study (Ferrari et al., 2013).

Anxiety is marked by a sense of fear and unpredictability, and is accompanied by worries about the future. As with depression, it can be a clinical disorder or can represent a tendency to experience an anxious state frequently or in response to specific situations. Symptom duration for the establishment of diagnosis varies among adolescents and adults. Anxiety

disorders are also highly prevalent. According to the National Comorbidity Survey, the prevalence of life time history of any anxiety disorder is 36.3 percent for women and 25.3 percent for men, with the most prevalent subtypes being social phobias and specific phobias (Kessler et al., 2005). Anxiety, like depression, affects a patient's overall quality of life, functioning, and ability to adhere to medical and rehabilitation regimens.

## Evidence of Association with Health

The impact of depression on health has been summarized in a number of qualitative and quantitative reviews. For example, a meta-analysis of 146,538 participants in 54 observational studies showed that depression predicted all-cause mortality and fatal coronary heart disease and incident myocardial infarction (Nicholson et al., 2006). Subanalyses showed that studies that used clinical measures of depression revealed stronger associations between depression and these outcomes than those that used symptom measures in populations without cardiovascular heart disease patients; however, they found weaker associations in studies of cardiovascular heart disease patients. Another meta-analysis involving 206,641 participants enrolled in 17 studies showed an association between depression and a subsequent risk of stroke (Dong et al., 2012). In 76 prospective studies, major depression and higher levels of depressive symptoms predicted mortality among cancer patients (Pinquart and Duberstein, 2010), and depressive symptoms were found to reduce active life expectancy among older adults (Reynolds et al., 2008).

Depression can also be a consequence of poor health and related conditions such as disability (Breslau et al., 2003; Dantzner et al., 2008; Luppino et al., 2010), suggesting that it has a bidirectional relationship with health problems such as diabetes (Golden et al., 2008). Depressed individuals are more likely to smoke, engage in physical activity less often, and be less compliant with medical regimens (Katon, 2011). Both antenatal and postpartum depression increase adverse outcomes, including negative effects on child development (Wisner et al., 2013).

A meta-analysis of 20 prospective studies showed that anxiety predicts incident coronary heart disease, with more robust effects found for cardiac mortality (Roest et al., 2010). Like persons with high levels of other negative emotions, anxious persons tend to engage in risky health behaviors (Thurston et al., 2013). The associations are apparent for individuals with both high levels of anxiety symptoms and anxiety disorders.

## Usefulness

If individual health care providers have formation on their patients' depression or anxiety, they can refer patients to counseling and other support services. The U.S. Preventive Services Task Force (USPSTF) recommends that health care providers screen adults and adolescents (12 to 18 years of age) for depression if staff-assisted depression care supports are in place to ensure an accurate diagnosis, effective treatment, and follow-up (Grade B recommendation) (USPSTF, 2009). USPSTF concludes that the current evidence (as of March 2009) is insufficient to assess the benefits and harms of screening children 7 to 11 years of age (USPSTF, 2009).

If the health system has information on their populations' screening and treatment needs, they can plan for appropriate services (including ongoing psychotherapy and pharmacotherapy treatments) as part of the mental health parity required by the Patient Protection and Affordable Care Act.<sup>6</sup> They also need to plan for ways to link patients to treatment given evidence that a diagnosis of depression or anxiety is often not enough to lead patients to seek treatment (Kravitz et al., 2013). A Cochrane review of randomized clinical trials using a collaborative care model for the treatment of depression and anxiety reported short- to long-term benefits for adult participants, including better compliance with medications, better mental health quality of life, and patient satisfaction (Archer et al., 2012). This model is not based on the individual practitioner model but on health systems as the foundation for implementing treatment and behavioral change.

If researchers have information on individuals' depression or risk for depression, the burden of this illness can be identified in subpopulations and risk factor stratification for comorbid diseases can be developed. Furthermore, studies attempting to prevent the onset of depression during high-risk periods, for example puberty, pregnancy, and menopause, can be designed and evaluated.

# Psychological Assets: Conscientiousness, Patient Activation, Optimism, and Self-Efficacy

Psychological assets include indicators such as life purpose, positive emotions and happiness, life satisfaction, conscientiousness, self-efficacy, and optimism. Not surprisingly, these indicators are correlated with one another and are generally negatively related to negative emotions. Nevertheless, sufficient empirical evidence exists to indicate that they should be considered separately from negative emotions. This section reviews the indicators conscientiousness, optimism, self-efficacy, patient activation.

<sup>&</sup>lt;sup>6</sup> Public Law 111-148.

Because of their covariation, the usefulness of these assets is discussed in aggregate below.

Conscientiousness refers to a family of traits that include the propensity to be self-controlled, to be task and goal directed, to delay gratification, and to follow norms and rules. It is often measured in the context of a taxonomy of personality dimensions labeled the Big Five: extraversion, agreeableness, emotional stability, openness to experience (or intellect), and conscientiousness (Roberts et al., 2012). Both children and adults can be assessed on dimensions of conscientiousness and the characteristics seem to be stable.

Self-efficacy concerns people's belief in their ability to attain specified goals. As defined by Bandura (2012), self-efficacy refers to evaluations within a specific domain of functioning, but, some theorists have conceptualized self-efficacy in a more general way, that is, confidence in one's ability to handle problems or challenges. The latter is closer to the concept of mastery or control. In either case, it is thought that increasing self-efficacy or a belief in one's capabilities can lead to improved affect, heightened motivation, and better clinical outcomes.

The committee employed the term "patient activation" to refer to the attitudes, skills, and knowledge of people that enables them to engage in health care in an active, full, and meaningful manner. Optimism is defined as the expectation that positive things will happen in the future (Segerstrom, 2005). It is usually assessed in terms of general expectations rather than expectations about how positive a specific future event is likely to be. An indirect assessment is based on people's view of the causes of past events, where an optimistic style refers to the extent to which individuals attribute positive outcomes to their own abilities and effort, stable qualities that extrapolate to a variety of situations, and attribute negative outcomes to unstable external factors that are outside their control and that are specific to the situation.

## Evidence of Association with Health

**Conscientiousness** In a meta-analysis of 20 mortality risk studies (Kern and Friedman, 2008), measures related to conscientiousness predicted longevity. The facets of conscientiousness related to mortality were achievement (persistent, industrious) and order (longitudinal, disciplined). Another meta-analysis of 194 studies (Bogg and Roberts, 2004) examined the association of conscientiousness with health behaviors. In general conscientiousness-related traits were positively related to beneficial health behaviors, for example physical activity, and negatively related to risky health behaviors, for example, cigarette smoking. Responsibility, self-control, and industri-

ousness were the facets most related to conscientiousness across health behaviors.

**Optimism** A 2009 meta-analysis using findings from 83 studies (Rasmussen et al., 2009), and combining 108 effect sizes showed that optimism was related to positive physical health overall and was specifically related to improvements to mortality, survival, cardiovascular outcomes, immune function, cancer outcomes, outcomes related to pregnancy, physical symptoms, and pain reduction. Significant associations were apparent in both cross-sectional and prospective studies. A subsequent qualitative review noted that out of all positive attributes, optimism was the most robustly associated with cardiovascular health (Boehm and Kubzansky, 2012). Optimists engage in more positive health behaviors and fewer health-damaging behaviors and cope with stressful circumstances in a more proactive fashion.

**Self-efficacy** Cross-sectional studies of self-efficacy revealed associations of self-efficacy with greater adherence to recommended regimens and to health outcomes. For example, self-efficacy is associated with less severe post-traumatic stress disorder (PTSD) and less fatigue, pain, and disability. The few longitudinal studies of trauma have shown associations of self-efficacy with less general distress and less PTSD symptom severity (Luszczynska et al., 2009).

Researchers have used the concept of self-efficacy to guide the design of intervention programs that include behavioral change. For example, a qualitative review of interventions based on self-efficacy theory applied to the management of chronic disease reported that behavioral interventions can lead to better self-efficacy for exercise, less severe asthma symptoms, improved communication with physicians, less emotional distress, and fewer health care visits (Marks and Allegrante, 2005).

**Patient activation** Most of the research linking patient activation, participation in care, and clinical outcomes has been published in the past 5 years. Evidence of the association of patient activation with patient participation in care exists. Several recent reports have indicated improved patient outcomes (i.e., limiting ED visits, obesity, and health services utilization) and improved patient activation scores with patient activation and patient participation in care (Brenk-Franz et al., 2013; Hibbard and Greene, 2013). Furthermore, a growing body of evidence shows that active patients have improved health outcomes and health care experiences; however, evidence about the impact on costs is limited to date (Hibbard and Greene, 2013). Even though a strong relationship has been shown to exist among health care decision making, patient activation, and health literacy, these concepts

exert distinct effects on patient participation in care and subsequent health outcomes (Smith et al., 2013).

## Usefulness

If individual health care providers have information on whether their patients are conscientious, optimistic, or pessimistic and score high or low on self-efficacy or patient activation, they can better anticipate difficulties their patients may have in being able to cope with specific chronic diseases, to follow a demanding medical treatment, or to introduce behavioral changes. Patients with low confidence in their ability to cope may benefit from additional health education programs based on evidence-based behavioral principles.

Health care providers can design or tailor clinical interventions to a particular patient situation. This tailoring may then allow health care providers to ensure that the expectations of participation and self-management generated by particular interventions align with the likelihood that the patient will meet expectations. Although many health care providers believe that patients can follow clinical instructions, the work of Hibbard and colleagues (2010) reveal that few providers support patient self-direction and independent choice.

If the health system has information on their populations' positive psychological assets, they can screen for the subgroups that are low in assets for referral to evidence-based programs that will support them when they are dealing with new life-changing diagnoses and planning appropriate treatments. By design, these programs do not target the enhancement of one asset but target the enhancement of multiple assets. Components of these interventions facilitate knowledge of the disease or behavior in question, identify achievable outcomes and unrealistic expectations, teach problemsolving and organizational skills, train participants to self-monitor and to identify high-risk situations, practice techniques to mitigate physiological arousal and stress, and provide exposure to others trying to master similar challenges. These interventions are often delivered in a group setting but can be administered to individuals, or given by a computer or the Internet, although less evidence about the efficacy of delivery by a computer or the Internet is available (Portnoy et al., 2008). It is thought that these components should improve coping skills, increase positive effects, reduce negative expectations about the future, and increase the level of shared decision making.

If researchers have information on an individual's positive assets, they can identify those subpopulations that are at the greatest disadvantage. Such information may also allow the development and testing of interventions to enhance positive assets in subpopulations at the highest risk for

specific diseases, although the evidence suggests that positive assets have a general influence on morbidity and mortality, but not on one disease. The prenatal and childhood origins of positive assets can be investigated with the long-term goal of enhancing the health of the nation.

### **Dietary Patterns**

Dietary patterns (summary measures of food consumption) are increasingly being examined to determine their association with health and to capture the complexities of dietary intake (McNaughton et al., 2008). A common dietary pattern associated with better health (called a "prudent dietary pattern") is characterized by higher intakes of legumes, whole grains, fish, fruit, vegetables, and poultry. A pattern associated with poorer health (referred to as a "Western diet") is characterized by higher intakes of refined grains, fried foods, red and processed meats, and desserts (Lopez-Garcia et al., 2004).

Few individuals have healthful dietary patterns. Many international and national guidelines recommend the consumption of at least five portions of a combination of vegetables and fruits a day, which equates to 80 grams per serving (Agudo, 2005; USDA and HHS, 2010), however, only 27 and 33 percent of the people in the United States meet the goal for vegetable and fruit intake, respectively (CDC, 2009). For example, less than 20 percent of individuals in a study of male college students met the daily recommendations for the intake of fruit and vegetable servings, the fatty acids eicosapentaenoic acid (EPA) and docosahexaenoic acid (DHA), dietary fiber, and saturated fat (Cessnun et al., 2011). Three-quarters of Californians with a diagnosis of coronary heart disease were estimated to not be eating healthful amounts of fruits and vegetables (Bellow et al., 2011).

### Evidence of Association with Health

Diet is a major determinant of health, and the consumption of low levels of fruits and vegetables (less than 400 grams per day) is considered to be among the top 10 risk factors for global mortality, resulting in 1.7 million global deaths annually (WHO, 2014).

Dietary patterns have been linked to health throughout the life course. For example, in a National Birth Defects Prevention Study, neonates born to mothers who adhered to a Western diet were 20 percent more likely to have an atrial septal heart defect (an abnormal hole between the upper left and right heart chambers) than those born to mothers who adhered to a prudent diet (Sotres-Alvarez et al., 2013). In a recent nested case-control study, infants diagnosed with a food allergy by age 2 were more likely to

have been introduced to solid foods at or before 16 weeks of age and were less likely to have received breast milk when cow's milk protein was first introduced into their diet (Grimshaw et al., 2013).

A diet consisting of salad, fish, and cereal grains were associated with lower diastolic blood pressure among adolescents between 16 and 18 years of age (McNaughton et al., 2008). An important challenge among adolescents is their high levels of fast-food consumption. For example, a 2001 study found that 75 percent of teenagers living in Minnesota eat at fastfood outlets at least once a week (French et al., 2001). Sugar-sweetened beverage consumption has been shown in observational and randomized controlled trials to promote weight gain in both children and adults (Malik et al., 2013).

Among adults, many studies document the relation of dietary patterns to the health of both men and women. High levels of consumption of fruits, vegetables, breads, grains, and dairy products have been associated with reduced cardiovascular mortality (Bongard et al., 2012). For example, in a meta-analysis (Salehi-Abargouei et al., 2013), a diet like that used in the Dietary Approaches to Stop Hypertension (DASH) (a diet rich in vegetables, fruits, and low-fat dairy foods) study found to significantly protect against cardiovascular disease, coronary artery disease, stroke, and heart failure risk by 20, 21, 19, and 29 percent, respectively. Additionally, increased consumption of all vegetables was associated with a lower risk of development of leukemia in the Iowa Women's Health Study (Ross et al., 2002). Adherence to a Mediterranean diet was associated with a lower incidence of gestational diabetes and a lower incidence of major cardiovascular events (Estruch et al., 2013; Karamanos et al., 2014). Furthermore, the Lifestyle Heart Trial, found that intensive lifestyle changes, including maintenance of a whole-foods vegetarian diet with 10 percent fat, led to greater regression of coronary atherosclerosis that was sustained at 5 years of follow-up (Ornish, 1999; Ornish et al., 1998, 1999).

Individuals, in older adulthood, that change their dietary patterns have positive health effects. For example, older adults who consumed the diet used in the DASH study, which allowed them to decrease their sodium consumption, experienced greater decreases in blood pressure than younger participants (Bray et al., 2004). Adherence to a Mediterranean diet was associated with a reduced number of new depressive symptoms in a prospective study of older adults (Skarupski, 2013).

# Usefulness

If individual health care providers have information on their patients' dietary patterns, they can recommend that their patients utilize ancillary services such as lifestyle counseling, including dietary counseling to

improve their patients' health. Counseling has been shown to be the most beneficial among high-risk patients, such as those with existing heart disease or diabetes (Fleming and Godwin, 2008). The provision of basic information, including recommended daily intakes of fruits and vegetables could lead to more healthful dietary patterns (Wardle et al., 2000; Watters et al., 2007).

If the health system has information on their populations' negative dietary patterns, they can use population-level approaches to address dietary patterns. Such approaches have proven successful in several settings, such as schools and communities. For example, some systems have established farmer's markets at their health care facilities to expand access to healthy foods for their patients. A recent pilot study showed that direct provision of healthy food to chronically ill patients reduced their subsequent rates of health care utilization and expenditures on health care (Gurvey et al., 2013).

If researchers have information on dietary patterns as part of the EHR, studies could identify interventions that should be used in clinical practice to enhance adherence to dietary advice in the context of a variety of chronic diseases (Desroches et al., 2013). These studies should evaluate outcomes, related costs, and potential differential effects across patient populations.

### **Physical Activity**

Activity can be divided into two behavioral categories: physical activity and sedentary behavior. Activity behaviors are often characterized by their frequency, duration, and intensity; organized by the contexts of leisure, occupation, household, or transport; and described contextually by dimensions of time, place, position, or person (Pettee et al., 2012).

Physical activity is defined as "any bodily movement produced by skeletal muscle resulting in energy expenditure above resting levels" (Caspersen et al., 1985, p. 126). Physical activity behaviors may be purposeful (e.g., running on a treadmill), part of daily life (e.g., mopping a floor), associated with work or school (e.g., play during recess or walking to work), or done for fun (e.g., a pickup basketball game or active games for children).

Sedentary behaviors, such as watching television, sitting quietly, and working at a desk, are behaviorally distinct from the high end of the physical activity domain, with different determinants for participation. It is possible for someone who is physically very active (e.g., does moderateintensity exercise for 1 hour per day) to be sedentary for many hours of the day. Measures of sedentary behavior complement measures of physical activity and provide different types of information about activity (Pate et al., 2008).

## Evidence of Association with Health

Physical activity is a modifiable determinant of health. A large body of empirical evidence demonstrates that higher levels of physical activity improve physical and psychosocial functioning, and reduce the risk of morbidity and mortality (Physical Activity Guidelines Advisory Committee, 2008) in a dose-response relationship (Powell et al., 2011). The benefits of physical activity accrue as levels over the baseline increase, but little evidence has shown that an upper threshold exists. These positive outcomes are mediated through a variety of physiological changes, such as increased autonomic balance, greater capillary density, higher insulin sensitivity, higher stroke volume, and reduced inflammation, to name a few (Powell et al., 2011). Sedentary behavior (measured as the amount of time spent sitting), however, has predominantly negative effects and has been associated in large population studies with higher risk of mortality, even after adjustment for level of physical activity (van der Ploeg et al., 2012).

Children's social competence and well-being are enhanced through participation in active sports and play (Lee et al., 2008). The built environment, such as parks and recreational facilities, provide children with the access to engage in such behavior and allows for the development of prosocial behavior (Tester and Baker, 2009). Compared with inactive youth, active children have higher levels of endurance and muscular strength, a reduced risk of obesity, more favorable cardiometabolic profiles, better bone health, and a lower risk of negative affect (Physical Activity Guidelines Advisory Committee, 2008). As children transition into adolescence their physical activity levels decline. This effect is more pronounced for girls than boys (Dumith et al., 2011). This transition continues into adolescents and young adulthood, ages 15 to 21, where regular vigorous physical activity and strength training begins to decline, this pattern is seen more in females than in males (Caspersen et al., 2000). These differences in physical activity between females and males are also seen in adulthood.

Among adults, physical activity has been associated with a variety of positive health outcomes such as improved mood, positive affect, and better sleep quality. It also reduces the risk of coronary artery disease, stroke, hypertension, type 2 diabetes, obesity, osteoporosis, breast and colon cancer, and depression (Penedo and Dahn, 2005; Physical Activity Guidelines Advisory Committee, 2008; Powell et al., 2011).

Physical activity has beneficial effects for older adults as well. Strong research evidence indicates that regular exercise can limit the progression of the chronic disease and disability associated with aging (Chodzko-Zajko et al., 2009). For example, home-based physical activity programs for frail elderly have been shown to reduce their rate of functional decline (Gill et al., 2002). Additionally, physical activity positively affects cognitive

functioning among elders (Davenport et al., 2012). It is also likely that the amount of physical activity (e.g., weight resistance) that women engage in as children and in early adulthood that increases their bone mass, protecting them against osteoporosis later in life, although more longitudinal research examining this life course association is needed (Baker et al., 2013). In older adults and in late life, the greatest effects are related to changes in vascular risk (Cornelissen and Fagard, 2005; Green et al., 2008; Hakim et al., 1999; Thompson et al., 2003).

# Usefulness

If individual health care providers have information on their patients' physical activity and find that they have low levels of physical activity, they can motivate and counsel them to increase their physical activity and reduce the amount of time that they are sedentary. Increasing the physical activity and reducing the sedentariness of the populations that they serve should beneficially influence outcomes (better health) at lower costs (lower need for resource-intensive specialty services), thereby enhancing the value of the health care services that they provide (Porter and Teisberg, 2007). For example, a recent study by Grant et al. (2013) found that systematically collecting exercise information during outpatient visits (e.g., how many times a week do you engage in moderate to strenuous exercise and length of time) was associated with significantly, yet small, changes in patient weight loss and HBA1c levels compared to those who were not asked about their physical activity levels.

If the health system has information on their populations' activity levels, they may participate in shaping local (and perhaps national) policies and collaborating in interventions for improving physical activity in schools, child care centers, and the built environment for improving physical activity (Subcommittee of the President's Council on Fitness, 2012). For example, multicomponent, school-based activity promotion interventions, including classroom activity breaks, enhanced physical education, active transportation to school, and active games before and after school have proved effective (Kriemler et al., 2011; Salmon et al., 2007).

## Tobacco Use and Exposure

Cigarette use and secondhand nicotine exposure pose many negative health risks, as smoking harms nearly every organ in an individual's body. Nicotine use increases the rates of many diseases and health consequences such as coronary heart disease, stroke, lung cancer, and obstructive lung diseases, as well as pregnancy complications (Fagerström, 2002). Secondhand smoke from lit cigarettes and cigars affects children and nonsmokers,

increasing their risk for negative health outcomes. More than 440,000 deaths annually are attributed to smoking and secondhand smoke (CDC, 2013f).

The impact of cigarette smoking and other tobacco use as a cause of significant morbidity and premature mortality is no longer disputed. The smoking habit most frequently begins before adulthood—the majority of adult smokers who smoke daily report that they started smoking before the age of 18 (CDC, 2012a). Fagerström (2002) and Doll et al. (2004) report that one-half of adult smokers die prematurely from tobacco-related diseases. The 2012 Surgeon General's report *Preventing Tobacco Use Among Youth and Young Adults* presents a comprehensive synthesis of the findings of the many scientific reviews conducted on the relationship between tobacco use and chronic diseases (CDC, 2012c). The CDC reported in 2011 that about one-fifth of U.S. adults aged 18 years and older were current smokers and that although smoking rates have been declining over the past few decades the rate of decline in women has been slower than that in men (CDC, 2011).

Smoking also contributes to health disparities. Smoking rates are three times higher among women with 9 to 11 years of education than among women who have an undergraduate degree, and this difference increases among pregnant women. Approximately 33.6 percent of pregnant women with 9 to 11 years of education who smoke versus 9.7 percent of pregnant women that are college graduates smoke. Women with incomes below the federal poverty level smoke more than women with incomes above the federal poverty level (31.5 percent versus 19.6 percent, respectively) and Native American women are more likely to smoke than Latina, white, or black women (Dube et al., 2009).

# Evidence of Association with Health

Observational research studies show that smoking results in an increased risk of cancers of the larynx, oral cavity, esophagus, stomach, bladder, kidneys, and pancreas (HHS, 1980, 2001, 2004). Smoking poses specific risks for women and is linked to an increased risk of cancers of the cervix and vulva (IOM, 2010a). Smoking during pregnancy can result in placenta previa and placental abruption (IOM, 2010a), and a relationship has been established between maternal smoking during and after pregnancy and sudden infant death syndrome (CDC, 2012c). Smoking is also linked to menstrual problems, reduced fertility, and premature menopause (Gold et al., 2001; Laurent et al., 1992; Luborsky et al., 2003). For women smokers using oral contraceptives, the risk of heart attack is increased by a factor of 30 and the risk of stroke is increased by factor of three compared with the risk for nonsmokers using oral contraceptives

(IOM, 2010a). The risk of developing lung cancer is about 13 times higher among women who smoke cigarettes than those who have never smoked. Among men who smoke cigarettes, their risk of developing lung cancer is 23 times higher than those men who have never smoked (CDC, 2012d).

The evidence is sufficient to determine that a relationship exists between smoking and nicotine use beginning in adolescence and young adulthood with harmful health effects. In addition, a causal relationship exists between active smoking and impaired lung growth, increased weight, increased phlegm production, decreased physical activity, and reduced lung function when an individual smokes during childhood and adolescence (CDC, 2012c). Asthma symptoms were significantly more prevalent in children whose parents were smokers than those who had nonsmokers for parents (Jang et al., 2004)

Nonsmokers who are exposed to secondhand smoke at home, at work, or in other enclosed spaces increase their heart disease risk by approximately 28 percent and their lung cancer risk by approximately 28 percent (CDC, 2013e). Individuals with PTSD have higher rates of cigarette smoking and nicotine dependence coupled with lower rates of quitting compared with the rates for individuals without PTSD (Hapke et al., 2005).

## Usefulness

If individual health care providers have information on their patients' nicotine use and exposure to secondhand smoke, they can prescribe validated interventions that can reduce their risks. Even a brief discussion of smoking risk has been linked to some patients quitting smoking and counseling recommended by the primary health care provider or received from nicotine addiction specialists can have even better outcomes (USPSTF, 2013a). Because of the strong associations between tobacco use and child and adolescent development, health care providers should be encouraged to understand the smoking behaviors of their patients and the parents of their patients (Park, 2011). Knowledge of an individual's smoking status will allow providers to better target efforts to prevent nonsmokers and children from being exposed to secondhand smoke. People suffering from PTSD might need additional help in cessation efforts, so knowledge of the comorbidity will be helpful to health care providers (Hapke et al., 2005) and the health system.

If the health system has information on their populations' nicotine use, they may be able to develop more effective treatments and prevention programs. Currently system-level programs, such as benefit packages that offer free smoking cessations services, have been shown to be cost-effective from a health system's perspective and from a community perspective (Hockenberry et al., 2012). The linking of individuals that smoke in com-

munities to smoking cessation programs is clearly an important element in smoking cessation efforts.

### Alcohol Use

Alcohol is one of the most widely used substances in the world. Alcohol use involves drinking beer, wine, or hard liquor. Alcohol use is more complicated than some other behavioral risk factors because it has both negative and beneficial effects on health, as alcohol use involves a continuum of risk (Mayo Clinic, 1998-2014). USPSTF defines alcohol misuse as a variety of behaviors, including the use of alcohol in a hazardous or risky manner, which means drinking more than the recommended daily, weekly, or per occasion amount (USPSTF, 2013b). Recreational low-risk levels of drinking have been identified to be no more than 14 drinks a week for men, and no more than 7 drinks a week for women (NIAAA, no date). The National Institute on Alcohol Abuse and Alcoholism defines "risky use" as drinking more than 3 drinks on any day or 7 drinks per week for women and more than 4 drinks on any day or 14 drinks per week for men (NIAAA, no date). The International Classification of Diseases, 10th Revision, Clinical Modification defines harmful alcohol use as a pattern that causes damage to physical or mental health (WHO, 2013). Even though the legal drinking age of 21 years in the United States, alcohol use by young individuals is also prevalent.

Excessive drinking accounted for approximately 88,000 deaths annually in the United States during 2006–2010, and an economic cost of \$224 billion in 2006 (McKnight-Eily et al., 2014).<sup>7</sup> Alcohol is also involved or implicated in more than one-third of motor vehicle deaths involving young drivers (between the ages of 21 and 24) (CDC, 2013d). According to the Substance Abuse and Mental Health Services Administration (SAMHSA) motor vehicle crashes are the leading cause of adolescent death among adolescents. In 2009, driving under the influence of alcohol at least once during the previous year was reported by approximately 4 percent of 16-yearolds and 9 percent of 17-year-olds (HHS and SAMHSA, 2012; SAMHSA, 2010). Underage drinking extracts a significant health toll and economic toll. The National Research Council and the IOM (2004) stimate the social cost of underage drinking to be \$53 billion. Underage alcohol use is also associated with education failure, suicide, and violence (NRC and IOM, 2004). The 2011 National Survey of Drug Use and Health notes that the rate of alcohol use among youths, ages 12 to 17 years, was 13.3 percent.

<sup>&</sup>lt;sup>7</sup> The prepublication version of this report incorrectly stated that the estimated economic cost of excessive alcohol use in 2006 was \$2.2 billion. This version of the report has been updated to reflect the correct figure of \$224 billion.

The same study reported that the rate of illicit drug use was approximately 17 times higher among young persons who both smoked cigarettes and drank alcohol (68.7 percent) than it was among those who neither smoked cigarettes nor drank alcohol (4 percent) (SAMHSA, 2012). Binge drinking peaks in the group aged 21 to 25 years and gradually declines thereafter (Fone et al., 2013; SAMHSA, 2001).

Evidence suggests that the prevalence of alcohol dependence and addiction varies by race ethnicity, and by sex. For example, in a 12-month prevalence study, men had greater alcohol dependence than women (6.9 versus 2.6, respectively) (Grant et al., 2004). In the same study, among women, Native American women had the highest prevalence of alcohol dependence (4.5 percent), followed by black women (2.4 percent), white women (2.4 percent), Latinas (1.9 percent), and Asian women (1.3 percent). In younger cohorts, a convergence in the ratio of alcohol dependence and addiction in males to females is occurring in all races except blacks.

# Evidence of Association with Health

High blood alcohol levels can suppress the central nervous system, which can lead to health consequences, including loss of consciousness, low blood pressure, respiratory depression, and death (CDC, 2013c; Sanap and Chapman, 2003). For example, the Low Birth Weight Registry reported that the use of alcohol during pregnancy contributed to nearly one-fourth of cases of low birth weight among infants. Blood alcohol levels in pregnant women can also affect the health of an unborn child. For example, use of alcohol during pregnancy is also compounded by nicotine use and drug abuse (Eisenhauer et al., 2011).

High levels of alcohol use have been associated with mental disorders and health disease. The most common comorbid conditions shown to occur in association with alcohol use have been found to be major depressive disorders, anxiety, and severe stress (Lai and Huang, 2009). Heavy drinking has also been positively associated with interpersonal violence among men in the military (Foran et al., 2012). A strong positive relationship between childhood maltreatment and heavy episodic parental drinking has also been found, indicating an indirect effect of childhood maltreatment and poor self-regulatory processes (Shin et al., 2012). Increased alcohol use can also lead to increased risky behaviors resulting in health disease. For example, young African American women having sexual intercourse with an intoxicated partner were 1.4 times more likely to develop a sexually transmitted infection (Crosby et al., 2008). Alcohol misuse also contributes to a wide range of health conditions, such as anxiety, depression, gastritis, liver disease, hypertension, cirrhosis, cognitive impairment, pancreatitis, and some cancers (Corrao et al., 2004).

## Usefulness

If individual health care providers have information on their patients' alcohol consumption, they can counsel those engaged in risky or hazardous drinking with brief behavioral interventions to reduce their alcohol misuse (USPSTF, 2013b). Evidence indicates that brief intervention sessions between a patient and their provider were effective in significantly reducing their weekly consumption of alcohol by nearly 4 drinks per week for adults. Interventions also reduced binge drinking episodes and were effective at increasing adherence to the recommended drinking limits (McKnight-Eily et al., 2014). Knowledge about an individual's alcohol consumption can help health care providers offer more effective and less risky means to manage stress and other problems (Bacharach et al., 2011).

If the health system is aware of community-level alcohol use through information in EHRs, it can become better equipped to develop appropriate programs and policies for reducing the risks of unhealthful levels of drinking. Establishment of links to community-based organizations and specialty services can aid health care professionals in patient counseling. For example, for men in the military, rates of heavy drinking and interpersonal violence were found to decrease when strong community support systems were in place, indicating that attention must be paid to stressors in the physical environment (Foran et al., 2012).

As with other health risk behaviors, if researchers have more information on the initiation and trajectories of drinking that can be linked to data on social and environmental drivers of the behavior, on the one hand, and to the biological underpinnings and consequences of alcohol use and prescription drug abuse, on the other. They can develop a more accurate understanding of how to prevent abuse and ameliorate its effects.

## Social Connections and Social Isolation

Humans are inherently social creatures as a function of their biological, psychological, and sociocultural systems. Not surprisingly, therefore, aspects of their social relationships are fundamentally important determinants of their health and of the way in which they relate to and are affected by health care providers and systems. The impacts of social relationships on health rival or exceed those of major biomedical factors (e.g., high blood pressure, cholesterol, and blood sugar) and behavioral factors (e.g., smoking, diet, obesity, physical activity, and alcohol consumption) (Berkman et al., 2004a; Holt-Lunstad et al., 2010; Pantell et al., 2013; Seeman et al., 2003).

The quantity and quality of an individual' social relationships can be conceived of in several important ways. The first one is social integration

or isolation, or the degree to which a person has social ties or relationships with other individuals, groups, or organizations. Theoretical and empirical work has especially focused on several areas involving relationships:

- Marital or partner status,
- Frequency of contact with other friends and relatives,
- Membership and frequency of participation in voluntary organizations, and
- Frequency of attendance at religious services.

Other forms of social relationships/engagement are sometimes considered, including participation in political, civic, or governmental groups and activities.

The second way in which social relationships can be understood is the level of social support, which refers to the actual aspect or perceived support or a benefit that a person derives from such relationships. Analysts often distinguish between instrumental, emotional, and sometimes other types of support, and between the perceived availability versus actual receipt of such support. The third way is to understand social relationships is a person's level of loneliness, or the psychological or subjective feeling of being alone or not connected with others. Loneliness is not the same as objective assessments of social isolation. An individual can lead a relatively solitary life and not feel lonely; conversely, an individual with many social contacts may still experience loneliness. Loneliness is the distressing feeling associated with perceiving that one's needs for social interaction are not being met in terms of either quantity or quality and suggests a discrepancy between desired and available relationships (Walton et al., 1991). One hypothesis about loneliness posits that it undermines a person's ability to self-regulate (Cacioppo and Hawkley, 2009; Cacioppo et al., 2006).

## Evidence of Association with Health

Social relationships, or a lack thereof, were linked with suicide in the late 19th century by one of the founders of modern sociology, David Émile Durkheim (1897). Over the course of the 20th century, this linkage was expanded to a broader range of mental health problems (Gurin et al., 1960; Srole et al., 1962; Veroff et al., 1981).

Since the late 1970s, social isolation and low levels of social integration have been shown to predict all-cause mortality and disease-specific indicators of morbidity, functioning, disability, and mortality, netting a wide range of biomedical and psychosocial confounders (Berkman and Breslow, 1983; Berkman and Syme, 1994; Berkman et al., 2000; Brummett et al., 2001; Holt-Lunstad et al., 2010; House, 2001; House et al., 1988). Various

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types of social relationships are associated with different aspects of health. For example, marital status tends to be more predictive of positive health for men than for women (Gove, 1973; Lillard and Panis, 1996; Marks and Allegrante, 2005). Attendance at religious services has consistently been shown to be protective against early mortality (McCullough et al., 2000). Indices that combine these indicators are more predictive of health than any one component, with low levels of integration or isolation being the most strongly related to poor health. The pathways or mechanisms explaining these relationships are multiple, but they are not yet clearly understood (House, 2001).

Many small-scale studies and some larger population studies have generally found that social support either in a direct or additive relationship or in a buffering or interactive one, is associated with many indicators of health, in which support mitigates or moderates the adverse effects of other risk factors for health, especially acute or chronic stress (Bowen et al., 2013; Cohen, 2004; Cohen and Wills, 1985; Dour et al., 2013; Sarason et al., 1990a,b). Of the various forms of support, the evidence most strongly supports the health-protective effects of perceived and emotional support. Under some circumstances, receipt of certain types of support has been linked to poorer health status (see, for example, Rook [1984] and Rook et al. [2012]).

Although most, if not all, people experience moments of loneliness, the health effects of loneliness are most pronounced for individuals with chronic exposure which can accrue over time and accelerate the aging process (Hawkley and Cacioppo, 2007). For example, the extent of loneliness experienced in childhood and adolescence predicts cardiovascular risk in young adulthood in an exposure-response type of relationship (Caspi et al., 2006). In both the Framingham Study (Eaker et al., 1992) and the National Health and Nutrition Study (Thurston and Kubzansky, 2009) women who experienced frequent bouts of loneliness had an increased risk of developing coronary heart disease. Loneliness was also found to accelerate cognitive decline in older individuals (Tilvis et al., 2004; Wu et al., 2006) and is an independent risk factor for depression, poor sleep, and lowered immune response (Luanaigh and Lawlor, 2008).

It remains unclear whether the effect of social isolation on mortality is independent of loneliness, whether loneliness mediates the effect, or whether both pathways are operative. In a large, prospective study of middle-aged adults, loneliness and social isolation were associated with increased mortality (Steptoe et al., 2013); however, in multivariate analyses the effect of loneliness was not found to be independent of its associations with sociodemographic characteristics and health conditions, whereas the effect of social isolation was independent and was not explained by loneliness.

Most of the relationships described above have been found to hold

across a wide range of the population by age, sex, gender, race, ethnicity, and socioeconomic level, though disadvantaged members of particular racial, ethnic, and socioeconomic groups have manifested lower levels of social integration and support (see, for example, the work of House [2002]). Differences between women and men in the relationships described above exist as well, with women receiving fewer health benefits than men from being married, and being more affected by the quality or supportiveness of their marriages and other relationships. Older people are particularly vulnerable to loneliness because of loss of family, friends, and resources. Although 1 in 10 children and youth report feeling lonely, nearly 1 in 3 older adults report feeling lonely at any one time (Masi et al., 2011).

### Usefulness

If health care providers know the social integration/isolation, social support, and loneliness of individual patients, they may better understand not only the patient's health but also their use of and need for health care services. People identify health problems and decide to utilize health care providers or systems by developing conceptions of their problems in life and functioning, and this development process occurs in a social context. Social relationships have been shown to affect preventive health behavior, cooperation, and compliance with treatment regimens and also to independently predict the likely course or progression of various illnesses (Spiegel et al., 1989; Umberson and Montez, 2010; Umberson et al., 2010). For dependent children or elderly patients, the quantity and quality of their relations with parents, guardians, or caretakers can enhance or impair their utilization of health care and its effects on them.

Identification of loneliness also gives providers an indication of risk and the need for more intensive involvement. For example, a meta-analysis of health care interventions for loneliness found that interventions that addressed maladaptive social cognition, negative thoughts of self worth, and other people's perception of the individual, rather than interventions involving strengthening social support or increasing social interactions have been the most successful (Masi et al., 2011).

If the health system is aware that social integration/isolation, social support, and loneliness can be major risk and protective factors for health, it can use this information to identify patients and work to assess and intervene at a population or community level. Innovations such as group visits may be particularly effective for those at risk. Such visits have shown promise in both primary care and prenatal care (Ickovics et al., 2007).

For researchers, the availability of more data on integration/isolation, social support, and loneliness can advance the knowledge of how much these determinants affect health and enable the establishment of better

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screening and treatment programs for loneliness and interventions within the health system, such as group visits, and community-based programs to strengthen social ties and support. This is a longstanding and vibrant research area, where little is known about the mechanisms or processes through which social integration/isolation, social support, and loneliness operate or about variations in the nature and mechanisms of their effects across health outcomes or populations which vary according to sociodemographic characteristics and in the level or nature of the health problems that they cause. EHRs would yield data uniquely valuable for research on these issues.

### Exposure to Violence

Interpersonal violence is defined as "behavior that threatens, attempts or causes physical harm" (Midei and Matthews, 2011, p. 159). Exposure to violence can occur throughout the life span and takes many forms, including physical violence, psychological violence, betrayal, and neglect. It includes trauma, bullying, child abuse, intimate partner abuse, and elder abuse. Different types of exposure to violence exist, such as violence that occurs in the community, violence that is witnessed, and violence that is personally experienced. The negative health consequences become more extreme as the strength and persistence of the exposure or experience increases.

Interpersonal violence affects many groups of individuals. National prevalence of interpersonal violence estimates ranges from 15 to 30 percent, whereas lifetime prevalence is 16 to 18 percent for young children and 25 to 27 percent for older children (Chen et al., 2013). Approximately 20 percent of pregnant women experience violence during a pregnancy. The prevalence of elder abuse is estimated between 2 and 10 percent of all elders (Lachs and Pillemer, 2004). These figures do not include community exposures, such as mass shootings, war, and violence shown by various media, which are recorded separately. However, communities subjected to such events and veterans should be considered special populations who may require more intensive screening.

### Evidence of Association with Health

Exposure to and the experience of violence have near-term and farreaching health consequences. Near-term harm arises from the specific violent acts, where nonfatal injuries outnumber fatalities by 2 to 1 (IOM and NRC, 2013b). Not all nonfatal injuries are physical, however; for example, psychological consequences and mood disorders also occur. Exposure to situations of abuse, such as intimate partner violence or maternal depres-

sion, leads to negative mental health outcomes, such as attention deficit/ hyperactivity disorder in children (Bauer et al., 2013) and heightened risk for eating disorders, drug and alcohol abuse, and depression in women (IOM, 2010b). The Adverse Childhood Experiences Study (ACES) of more than 17,000 adults who reported on their early experiences of abuse, neglect, or household dysfunction (CDC, 2013a) found increased rates of health risk behaviors (e.g., smoking, alcohol use), mental health problems (e.g., depression, suicide), and chronic diseases (e.g., chronic obstructive pulmonary disease, ischemic heart disease, lung cancer) as the number of reported childhood adversities increased.

The effects of exposure to violence are greater the earlier in life that the exposure happens and health consequences increase with more frequent exposures and experiences of violence. Trauma, abuse, neglect, and exposure to harmful stressors during childhood contribute to what are called "adverse childhood experiences" (CDC, 2013b). LGBT youth are more likely to have adverse experiences, such as physical and emotional abuse and sexual victimization, than among youth in the general population (IOM, 2013a). The effects of these experiences contribute to both shortand long-term health consequences, including depression, suicide attempts, sexually transmitted diseases, alcohol abuse, nicotine use, and liver disease, among others. These health consequences are compounded as the more often children experience abuse or neglect, the worse the health outcomes (CDC, 2013b). Abuse and neglect influence the course of development through alteration of both psychological and biological development, creating negative health outcomes in both psychological and physical health that extend into adulthood (IOM, 2013b). Child abuse may be confounded with co-occurrence of child maltreatment and reduced access to regular medical care, thus increasing use of emergency room visits. The health effects of this violence are most pronounced in early adulthood (Midei and Matthews, 2011).

Emerging evidence of neurological or neurohormonal mediators in the development of the health effects of violence has been found. Genderbased effects of violence have been observed both in youth and in young adults. Girls internalize the abuse experience and experience mood disorders, whereas boys externalize the abusive experience and become aggressive (Chen et al., 2013). Violence across the life span is often, but not exclusively, perpetrated by men against women. Nearly one-fourth of U.S. women experience interpersonal violence in their lifetime, while 15 percent of men report experiences of interpersonal violence. Interpersonal violence exposure is linked to concurrent and subsequent smoking, severe obesity, physical inactivity, depression, and suicide (IOM, 2010b).

Among elders, the most immediate probable physical effects include injuries, wounds, and welts and subsequent persistent physical pain and

soreness, sleep disturbances, nutrition and hydration issues, exacerbation of preexisting health conditions, increased risks for premature death, and increased susceptibility to new illnesses (AMA, 1990; Anetzberger, 2004; Lachs et al., 1998; Lindbloom et al., 2007).

## Usefulness

If individual health care providers know weather their patients are being exposed to or experiencing violence, they can create a comfortable space for their patient to disclose more about their experience, opening the door for appropriate care (see the vignette in Box 1-2 in Chapter 1). Screening and referral to an intervention (e.g., trauma-focused cognitive behavioral therapy) have been shown to strengthen psychological health and may mitigate the impact of violence on health outcomes (Cohen and Mannarino, 2008; Kiely et al., 2010; Nelson et al., 2004; Stein et al., 2003). The American Academy of Pediatrics (AAP) supports screening parents and children, but various protections need to be in place. Issues of potential mandatory reporting of child and elder abuse exist, and providers must keep in mind concerns that suggesting the possibility of abuse to a child increases the child's vulnerability. No evidence that screening to identify women at risk leads to increased risk, although concerns about screening mothers in front of children exists. Other interventions are possible if screening includes an assessment of access to firearms.

Despite controversy regarding intrusion on individual rights, the AAP's practice guide, *Bright Futures*, urges pediatricians to counsel parents who possess guns to place their firearms in a safe storage unit. The prevention of easy access to firearms may decrease the incidence of injury by as much as 70 percent. The guide also urges pediatricians to inform parents that the presence of guns in the household increases the risk for suicide among adolescents (AAP, 2012).

If the health system has information on population-level violence (i.e., intimate partner, child abuse, and gun violence) they can coordinate appropriate interventions and treatment plans both within their system and in the community. Interest has been growing in the field of trauma informed care, an integrated, coordinated approach that actively explores current and past exposures or experiences and drives care services on the basis of mental and physical health responses to and consequences of care (Ursano et al., 2012). A health system equipped with data on population-level exposures to violence and proximity to weapons can work with the judicial sector and schools (NRC, 2004b). Both the AAP and the IOM recommend greater emphasis on general quality and prevention strategies rather than specific, targeted efforts (AAP, 2012; IOM, 2010b).

If researchers have information on an individual's exposure to violence, coupled with new analytic tools, they can begin to determine the mechanisms of the effect between violence and health outcomes and the role of such mediators as negative affect and depressive symptoms. Potential biomarkers and neuroimaging may validate the emerging evidence of the effects of sustained stress, brain development, and neuroendocrine response on subsequent health. In light of the co-occurrence and potential exacerbating effects of other social and behavioral determinants (education level, psychological attributes such as impulsivity and substance abuse), information on experiences of, exposure to, and access to violence and the weapons of violence will help provide the data needed to advance a full understanding of health determinants and the ability to achieve precision medical care.

# Neighborhoods and Communities Compositional Characteristics

A number of domains of special relevance to the social determinants of health can be characterized by use of the patient's residential address. Some of these domains can be easily characterized by linking to existing datasets and readily available measures; others will require processing of other data to create meaningful measures. The exponential growth of geocoded datasets will likely allow linkage to a large set of potentially useful variables in coming years. In all cases appending these measures to the EHR will require accurate recording and tracking of a patient's home addresses over time. It will also require systematic geocoding, a process by which latitude and longitude coordinates are mapped with U.S. census geographical identifiers (down to the block group level) and are assigned to each address.

An important point is that these geographically linked data can capture health-relevant information that cannot be obtained directly from the patient. These measures capture aspects of the social and physical context in which an individual is operating and are often related to health or to health care outcomes over and above the individual-level characteristics of the patient. As noted in Chapter 2, the acquisition of information for an EHR through geocoding is not a simple task. Challenges include the lack of defined standards for reference data or methods for geocoding, inconsistent availability of community information systems to which EHR data can be linked, insufficient technical expertise in health systems to establish methods for linking, as well as limitations in expertise regarding patient privacy protocols. A description of area socioeconomic and racial/ethnic characteristics, which the committee viewed as being of special relevance and potential utility in characterizing social determinants, is used as an example in the material that follows.

Area socioeconomic and racial/ethnic characteristics include summary indicators of the socioeconomic and racial/ethnic composition of an area

## CAPTURING SOCIAL AND BEHAVIORAL DOMAINS IN EHRs

that can be created from routinely collected census data. Census tracts are commonly used to define the area because of their utility as proxies for residential neighborhoods. Examples of indicators include the median household income; poverty level; the number of persons who completed college; the number of persons in managerial, professional, or executive occupations; and the unemployment rate. Various summary indicators of area socioeconomic position derived theoretically or through the use of techniques such as factor analysis have been created (Diez-Roux and Mair, 2010). Indicators related to area racial/ethnic composition include the number of residents in various race/ethnic categories (e.g., African American, Latino, or Asian) as well as more complex indicators that contrast the composition of a given area with that of the broader area (e.g., the metropolitan statistical area, city, or region) in which it is embedded to capture the level of racial or ethnic segregation (Reardon and Firebaugh, 2002; Reardon et al., 2008; Wong, 1993). Similar indicators can be used for income to capture income segregation. Indicators of immigrant composition from foreign-born individuals can be used for gathering information.

# Evidence of Associations with Health

Indicators of area socioeconomic composition have been shown to be related to many different health-related outcomes, including behaviors and other risk factors for disease, morbidity, outcomes among persons with disease, and mortality (Diez-Roux and Mair, 2010; Gerber et al., 2008, 2011a,b). Area socioeconomic composition has been used as a proxy for the individual- or family-level socioeconomic position of residents when such data are not directly available and may also make an independent contribution. Attributes of SES in an area are related to some health outcomes even after measures of individual-level SES are controlled for (Diez-Roux and Mair, 2010). Moreover, indicators of area socioeconomic composition may serve as a proxy for a variety of features of neighborhood environments (including both physical and social features) that may be etiologically relevant to many different health-related processes. These are valuable in multilevel analyses that capture characteristics of both the individual and the community levels, and can be used to understand not only the independent contribution of both levels but also how neighborhood composition may moderate the impact of the individual's own characteristics on her or his health.

Attributes of racial segregation have also been linked to health (Fang et al., 1998; Kramer and Hogue, 2009; Subramanian et al., 2005; Williams and Collins, 2001). The processes involved may differ for different racial and ethnic groups. For example, individuals in segregated African American neighborhoods have been shown to have worse health independently of

the individual-level characteristics of residents, possibly because of strong inequities in the distribution of physical and social neighborhood resources that accompany segregation in the United States (Williams and Collins, 2001). In contrast, findings on neighborhoods with predominantly Latino and foreign-born individuals suggest that segregation can be health protective, possibly as a result of greater social support or lower levels of acculturation of residents to health-damaging aspects of U.S. lifestyles (see, for example, the work of Acevedo-Garcia and Bates, 2008; Eschbach et al., 2004). Although a large body of literature has investigated the associations of area income inequality with health, substantial debate continues to exist regarding whether the associations are causal (Kondo et al., 2009; Lynch et al., 2004) and whether measures of income inequality calculated for relatively small areas such as census tracts are meaningful and likely to have true causal effects on health.

## Usefulness

If the health care provider has knowledge of a patient's socioeconomic circumstances and neighborhood conditions, such information could be of use in making relevant treatment decisions. For example, measures of area SES may be of use in clinical settings for risk stratification (Fiscella and Franks, 2001; Fiscella et al., 2009; Franks and Fiscella, 2002; Franks et al., 2003a,b) and for prediction of outcomes of care (Chu et al., 2012; Koren et al., 2012; Koton et al., 2012). Other environmental indicators could be linked to the EHR through the use of geocoded address information. These include the neighborhood built environment, such as land use, urban design, and walkability; access to resources such as healthy foods, recreational facilities, or health care facilities; exposures to environmental hazards, such as lead, traffic and air pollution; and the degree of safety and crime.

If the health systems has information on the neighborhood SES of patients' neighborhoods, they can use this information to (1) generate descriptive data on patients' characteristics and (2) estimate rates of various conditions (and outcomes of care) for various social groups and geographical areas served by the system, practice, or provider. In addition to their descriptive value (including, potentially, the value for estimating risk-adjusted comparisons) these data could also be of use in the targeting of preventive interventions by providers, practices, and the health system (see, for example, Butler et al. [2013], Perrin [2002], and Wallerstein and Duran [2010]).

The availability of EHRs linked to area SES indicators would allow a description of trends and rates for geographical areas. This information

would be of use to public health agencies for the purposes of diagnosing community needs and targeting possible interventions (see, for example, McRae et al. [2008]).

If researchers have access to various characteristics of the SES of neighborhoods, they can use these data to determine if an association exits between these indicators and health or between these indicators and the outcomes of care. These data can also be used to develop, create, or expand targeted intervention and prevention programs. This would allow investigation of how the domains captured by area measures relate not only to disease development but also to the effectiveness of various interventions and outcomes of care.

## DOMAINS NOT INCLUDED

The table of the full set of domains, which the committee developed on the basis of its review of conceptual models of the determinants of health, is presented in Chapter 2, Table 2-1 of this report. Given the large number of domains, the committee needed to narrow these down to a candidate set for consideration for inclusion in all EHRs. The domains described in this chapter are those that the committee identified to be candidates best suited for consideration for inclusion in all EHRs, given the strength of the evidence of the domain's association with health and its potential utility if the domain was included in EHRs. In making challenging decisions, the committee was guided by a keen awareness that the time and resources needed to collect these data must be balanced by evidence of their value for the individual, the community, the health system, and/or for research purposes.

While the majority of candidate domains identified favor individual capacities and characteristics rather than social level issues, this reflects that data reported by individual patients is most accurate regarding their personal attributes and experiences. Characteristics of their social environment will require additional input; some of this can occur via potentially geocodable items such as area SES, while other information will require linkage to other data sources, a topic that will be addressed in the committee's next report.

Additionally, some of the domains identified in this report are strongly correlated with each other. For example, exposure to violence, as noted earlier, often results in depressive behavior or stress and/or anxiety. Also, the effectiveness of interventions to increase weight loss, in the absence of counseling on physical activity may be needed to reinforce and sustain healthy behaviors. The intent of the committee's Phase 2 report will be to identify measures under each domain specified in this report. Further, in order to prioritize any domains for inclusion in EHRs, the committee's full set of criteria will need to be applied.

The domains that were reviewed but that were not selected for inclusion in the candidate set of domains were theoretically linked to health but lacked an adequate evidence base to support routine collection of data for these domains. By limiting the recommended domains to those for which a reasonable evidence base exists, the committee is confident that the smaller set of domains and measures (which will follow in the committee's next report), if implemented, will result in the collection of crucial data for patient care, improvement of population health, and further expansion of the knowledge base to facilitate the development of precision medicine or other strategies for improving the health status of the U.S. population.

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# А

# Agendas of Public Meetings

## FIRST MEETING

September 24, 2013 The National Academies Keck Center 500 Fifth Street, NW Washington, DC 20001

11:00–11:15 a.m.	Welcome and Overview
	Nancy E. Adler, Ph.D.
	Committee Co-Chair

William W. Stead, M.D. Committee Co-Chair

11:15–11:25 Meaningful Use and Electronic Health Records *Kevin Larsen, M.D., F.A.C.P. Medical Director, Meaningful Use Office of the National Coordinator for Health Information Technology* U.S. Department of Health and Human Services

## 11:25–11:30 Questions from the Committee Members

114	CAPTURING SOCIAL AND BEHAVIORAL DOMAINS IN EHRS
11:30 a.m.– 12:30 p.m.	Presentation of the Charge to the Committee <b>Robert M. Kaplan, Ph.D.</b> Director of the Office of Behavioral and Social Sciences Research National Institutes of Health
	<b>William Riley, Ph.D.</b> Chief, Science of Research and Technology Branch Division of Cancer Control and Population Sciences National Cancer Institute, National Institutes of Health
	<b>Maureen Boyle, Ph.D.</b> Team Leader Health Information Technology Substance Abuse and Mental Health Services Administration
	<b>Robert Hahn, Ph.D., M.P.H.</b> Coordinating Scientist, Community Guide Branch Division of Epidemiology, Analysis and Library Services Center for Surveillance, Epidemiology and Laboratory Services Office of Public Health Scientific Services Centers for Disease Control and Prevention
	James Marks, M.D., M.P.H. Senior Vice President Robert Wood Johnson Foundation Lisa and John Pritzker
	The Lisa and John Pritzker Family Fund
12:30-12:40	Questions to the Sponsors by the Committee Members
12:40-1:00	Open Session* Opportunity for Attendee Comments *Note: If there are insufficient public comments to fill the allotted agenda period, the open session may end earlier than shown.
1:00	Adjourn

of

## SECOND MEETING

## November 25, 2013 University of California, San Francisco, Laurel Heights Building 3333 California Street San Francisco, CA 94118

8:30–8:40 a.m.	Welcome and Overview
	Nancy E. Adler, Ph.D.
	Committee Co-Chair
	William W. Stead, M.D.
	Committee Co-Chair
8:40–9:40	Panel 1
	Alan Glaseroff, M.D.
	Director, Stanford Coordinated Care
	Clinical Professor, Medicine
	Rishi Manchanda, M.D., M.P.H.
	President, HealthBegins
	Robert Kahn, M.D., M.P.H.
	Associate Director, Division of General and Community Pediatrics
	Professor, University of Cincinnati Department of Pediatrics
	Brigid McCaw, M.D., M.P.H., M.S., F.A.C.P.
	Medical Director, Kaiser Permanente
	Family Violence Prevention Program
9:40-10:05	Questions from the Committee Members
10:05-10:30	Panel 2
	Beverly Brumfield
	Patient/client and board member of Curry Senior
	Center

## Rashanda Lee Children's Hospital Oakland Family Advisory Council

116	CAPTURING SOCIAL AND BEHAVIORAL DOMAINS IN EHRS
	David McClure
	Family Health Center at San Francisco General Hospital
	Advisory board member
	Moderated by Laura Gottlieb, M.D., M.P.H., Assistant Professor of Family and Community Medicine at the University of California, San Francisco
10:30-10:40	Questions from the Committee Members
10:40-11:30	Open Session* Opportunity for Attendee Comments *Note: If there are insufficient public comments to fill the allotted agenda period, the open session may end earlier than shown.
11:30	Adjourn

## В

# Committee Biographies

Nancy E. Adler, Ph.D. (Co-Chair), is a professor of psychology in the Departments of Psychiatry and Pediatrics at the University of California, San Francisco, where she is also vice chair of the Department of Psychiatry and director of the Center for Health and Community. She received a B.A. from Wellesley College and a Ph.D. in psychology from Harvard University. Her research spans two areas. One focuses on health behaviors, investigating why individuals engage in health-damaging behaviors and how their understanding of risk affects their choices. This research has primarily been in reproductive health, examining adolescent decision making regarding contraception, conscious and preconscious motivation for pregnancy, perceptions of risk of sexually transmitted diseases, and use of reproductive technologies for infertility. Her second area of work is on the impact of socioeconomic status (SES) on health and the role of psychosocial mediators. As chair of the MacArthur Foundation Network on SES and Health, her interests span levels of analysis to examine (1) how social, psychological, and biological factors associated with SES act together to determine the onset and progression of disease and (2) how the relationship of SES and health may differ depending on gender and ethnicity. She has been testing a measure of subjective social status (the MacArthur "ladder"), which is designed to capture an individual's global sense of their status. One version of the ladder assesses standing on traditional SES indicators, whereas another assesses standing in one's community. Both are showing strong associations with health outcomes across a range of populations.

William W. Stead, M.D. (*Co-Chair*), is associate vice chancellor for health affairs, chief strategy officer, and director of the Informatics Center at Vanderbilt University Medical Center. Dr. Stead is the McKesson Foundation Professor of Biomedical Informatics and Professor of Medicine and a founding fellow of both the American College of Medical Informatics and the American Institute for Engineering in Biology and Medicine. He is a member of the National Committee on Vital and Health Statistics and an elected member of the American Clinical and Climatological Association, and he served as president of the American College of Medical Informatics. Dr. Stead received a medical degree from Duke University, where he also completed specialty and subspecialty training in internal medicine and nephrology.

Kirsten Bibbins-Domingo, Ph.D., M.D., M.A.S., is the Lee Goldman MD Endowed Chair in Medicine and a professor of medicine and of epidemiology and biostatistics at the University of California, San Francisco (UCSF). She is a general internist and attending physician at San Francisco General Hospital and the director of the UCSF Center for Vulnerable Populations at San Francisco General Hospital. Dr. Bibbins-Domingo is an active researcher in preventive cardiology, the epidemiology of cardiovascular disease in young adults, and race and gender health and health care disparities. Her research has examined the development of cardiovascular risk factors in young adults, the effectiveness of screening and diagnostic tests for cardiovascular disease, and computer-simulated projections of future cardiovascular disease trends and the impact of public health and clinical interventions on cardiovascular disease prevention. She is an inducted member of the American Society for Clinical Investigation and a member of the U.S. Preventive Services Task Force. Dr. Bibbins-Domingo received an undergraduate degree in molecular biology and public policy from Princeton University and a medical degree, a Ph.D. in biochemistry, and master's of clinical research from UCSF.

Patricia Flatley Brennan, R.N., Ph.D., F.A.A.N., is professor in the Department of Industrial and Systems Engineering and the Moehlman Bascom Professor in Nursing at the University of Wisconsin, Madison. Dr. Brennan's work ranges from the development and evaluation of computer networks as a mechanism for delivering nursing care to homebound ill persons and their caregivers to stimulating innovation in personal health records, with particular attention to patient-defined and patient-generated data. Her most current projects include exploring how individuals and families manage health information in their homes and evaluating the adoption of novel health information technology architectures. She has served on the Board on Mathematical Sciences and Their Application of the National Academy

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of Sciences and on several Institute of Medicine (IOM) committees, including the Committee on Enhancing the Internet for Biomedical Applications: Technical Requirements and Implementation Strategies (1998 to 2000) and the Committee on the Review of the Adoption and Implementation of Health IT Standards by the Department of Health and Human Services Office of the National Coordinator for Health Information Technology (2007). Dr. Brennan is fellow of the American Academy of Nursing (1991) and the American College of Medical Informatics (1993). She has been an IOM member since 2001. Dr. Brennan has a Ph.D. in industrial engineering from the University of Wisconsin, Madison, and received an M.S.N. from the University of Pennsylvania.

Ana Diez-Roux, M.D., Ph.D., M.P.H., is dean of the Drexel University School of Public Health. She was formerly a professor and chair of epidemiology and director of the Center for Social Epidemiology and Population Health at the University of Michigan School of Public Health. She is also a research professor in the Survey Research Center in the Institute for Social Research at the University of Michigan. She received an M.P.H. and a Ph.D. from the Johns Hopkins University of School of Hygiene and Public Health and an M.D. from the University of Buenos Aires, Argentina. Dr. Diez-Roux's research interests and projects focus on social epidemiology, neighborhood health effects, racial and ethnic disparities, and systems approaches in population health.

Christopher Forrest, M.D., Ph.D., is a professor of pediatrics and health care management at the University of Pennsylvania and Children's Hospital of Philadelphia. He is a general pediatrician who has run inpatient units and primary health care centers. He leads a research center that focuses on the theory and measurement of health across the life course, value in pediatric health care, and development of a national pediatric learning health system. He provides leadership for a federally funded Pediatric Quality Measures Program Center of Excellence, a national program in pediatric learning health systems (which are dedicated to advancing the health of children through research, quality improvement, and informatics), the National Children's Study health measurement network, and the National Institutes of Health's Patient Reported Outcome Measurement Information System's Executive Committee. Dr. Forrest received B.A. and M.D. degrees at Boston University as part of a dual-degree program and completed a Ph.D. in health policy and management at the Johns Hopkins Bloomberg School of Public Health.

James S. House, Ph.D., is the Angus Campbell Distinguished University Professor of Survey Research, Public Policy, and Sociology at the Univer-

sity of Michigan. His research interests include social psychology, political sociology, social structure and personality, psychosocial and socioeconomic factors in health, survey research methods, and American society. Dr. House has worked in sociology and social epidemiology to understand the effects of broader social structures and processes on people's attitudes, behaviors, well-being, and especially health. His and his colleagues' research has helped to demonstrate the adverse effects of occupational and other forms of stress on health and how social relationships and supports can buffer or mitigate the deleterious health effects of stress and promote health more generally. Over the past two decades he has focused on describing and understanding social disparities in health over time and the life course, especially by socioeconomic position. Dr. House is a member of the American Academy of Arts and Sciences, the National Academy of Sciences, and the Institute of Medicine. He has served on the National Research Council's Panel on Race, Ethnicity, and Health in Later Life. Dr. House received a Ph.D. in social psychology from the University of Michigan.

George Hripcsak, M.D., M.S., is professor and chair of Columbia University's Department of Biomedical Informatics and director of Medical Informatics Services for New York-Presbyterian Hospital/Columbia Campus. Dr. Hripcsak is a board-certified internist with degrees in chemistry, medicine, and biostatistics. He led the effort to create the Arden syntax, a language for representing health knowledge that has become a national standard. Dr. Hripcsak's current research focus is on the clinical information stored in electronic health records (EHRs). Using data-mining techniques such as machine learning and natural language processing, he is developing the methods necessary to support clinical research and patient safety initiatives. As director of medical informatics services, he oversees a 7,000-user, 4 million-patient clinical information system and data repository. He is currently cochair of the Meaningful Use Workgroup of the Office of the National Coordinator of Health Information Technology, U.S. Department of Health and Human Services (HHS); it defines the criteria by which health care providers collect incentives for using EHRs. Dr. Hripcsak was elected fellow of the American College of Medical Informatics in 1995 and served on the Board of Directors of the American Medical Informatics Association (AMIA). As chair of the AMIA Standards Committee, he coordinated the medical informatics community response to HHS for the health informatics standards rules under the Health Insurance Portability and Accountability Act of 1996. Dr. Hripcsak chaired the National Library of Medicine's Biomedical Library and Informatics Review Committee, and he is a fellow of the American College of Medical Informatics and the New York Academy of Medicine and a member of the Institute of Medicine. He has published more than 250 papers.

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Mitchell H. Katz, M.D., is the director of the Los Angeles County, California, Department of Health Services, the second largest health system in the nation. Previously, he was the director of health for the City and County of San Francisco for 13 years. Prior to becoming the director in San Francisco, he served the department in a number of positions, including director of the AIDS Office and director of the Emergency Medical Services Agency. He practices medicine as a primary care doctor at the Edward R. Roybal Comprehensive Health Center.

Eric B. Larson, M.D., M.P.H., M.A.C.P., is vice president for research and executive director at Group Health Research Institute (GHRI). His research has changed how people think about healthy aging. Dr. Larson is a member of the Institute of Medicine and a national leader in geriatrics research. A general internist, Dr. Larson has pursued an array of research, ranging from clinical interests such as Alzheimer's disease and genomics to health services research involving technology assessment, cost-effectiveness analysis, and quality improvement. His research on aging includes a long-standing collaboration between Group Health and the University of Washington (UW) called the Adult Changes in Thought (ACT) study. ACT's many groundbreaking results include news linking exercise to later onset of dementia. Several of Dr. Larson's research projects are related to promoting successful aging and high functioning in seniors. With colleagues at UW, he is executive coproducer of the Art of Aging, a newsmagazine series on public television and the Internet. Dr. Larson strives to keep GHRI on the cutting edge of health research. He has provided leadership on several new initiatives, including serving as principal investigator of a National Institutes of Health roadmap project to expand the capacity of the HMO Research Network, launching GHRI research programs in health informatics and obesity, and evaluating the Medical Home model at GHRI. In 2008, Dr. Larson facilitated GHRI's inclusion in the UW's new Northwest Institute for Genetic Medicine, a collaboration among local research institutions to support the translation of genetic research into clinical care. He has also established a formal affiliation agreement with the UW School of Public Health and strengthened the Institute's relationship with its partners in the GHRI health care delivery system. Dr. Larson served as medical director for the UW Medical Center and associate dean for clinical affairs at its medical school from 1989 to 2002. He is a member and past president of the Society of General Internal Medicine, having received its highest honor, the Robert J. Glaser Award, in 2004. Dr. Larson is also a master of the American College of Physicians and served on its board of regents for nearly a decade, including one term as chair. He has been a commissioner on The Joint Commission since 1999.

Karen A. Matthews, Ph.D., is a distinguished professor of psychiatry and professor of epidemiology and psychology at the University of Pittsburgh. For more than three decades, Dr. Matthews and her research group have investigated the psychosocial characteristics of individuals and their early life experiences that ultimately lead to coronary atherosclerosis and hypertension later in life. They have focused on two stages of the life span when change in cardiovascular risk reliably occurs, adolescence and mid-life, because change provides an optimal setting for observing how hormonal and other biological processes, social roles, and psychological characteristics interact to accelerate an individual's cardiovascular risk. Their approach cannot rely on the methodologies and concepts from a single discipline or field because of the limitations of a single field and the nature of the scientific problem. Dr. Matthews and her research group thus benefit from the knowledge and methods derived from psychology, psychiatry, epidemiology, and cardiology. Dr. Matthews has published in scholarly journals and has received various honors and awards, including the American Psychological Association Award for Distinguished Scientific Applications of Psychology and the American Psychosomatic Society President's Award. In 2002, she became a member of the Institute of Medicine. Dr. Mathews earned a Ph.D. at the University of Texas, Austin.

David Ross, Sc.D., is director of the Public Health Informatics Institute. He became the director of All Kids Count, a program of the Institute supported by the Robert Wood Johnson Foundation (RWJF), in 2000, and subsequently began the Institute, also with funding from RWIF. His experience spans the private health care and public health sectors. Before joining the Task Force, Dr. Ross was an executive with a private health information systems firm, a Public Health Service officer with the Centers for Disease Control and Prevention (CDC), and an executive in a private health system. Dr. Ross holds a doctoral degree in operations research from Johns Hopkins University (1980), where he was involved in health services research. After serving as director of the Health Service Research Center, Baltimore, Maryland, U.S. Public Health Service Hospital, he became vice president for administration with the Wyman Park Health System. In 1983, he joined the CDC's National Center for Environmental Health. During his career at the CDC, he worked in environmental health, the CDC's executive administration, and public health practice. Dr. Ross was founding director of the Information Network for Public Health Officials, the CDC's national initiative to improve the information infrastructure of public health. His research and programmatic interests reflect those of the institute: the strategic application of information technologies to improve public health practice.

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David R. Williams, Ph.D., M.P.H., is the Norman Professor of Public Health and a professor of African and African American Studies and of sociology at Harvard University. His prior academic appointments were at Yale and the University of Michigan. Dr. Williams is interested in the patterns, trends, and determinants of variations in disease and death by race and socioeconomic status. His research has examined the extent to which a broad range of social and psychological factors are linked to social status and can explain social variations in physical and mental health. He is especially interested in the complex ways in which social class and race/ ethnicity combine to affect health and in identifying the mechanisms and processes by which racism, at both the societal and individual levels, can affect the incidence, prevalence, and course of disease. He is also a former member of the U.S. Department of Health and Human Services' National Committee on Vital and Health Statistics. Capturing Social and Behavioral Domains in Electronic Health Records: Phase 1