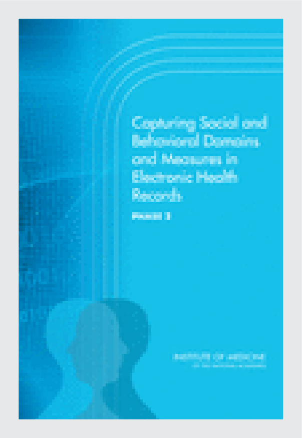

Capturing Social and Behavioral Domains and Measures in Electronic Health Records: Phase 2

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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

Capturing Social and Behavioral Domains and Measures in Electronic Health Records

PHASE 2

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

Board on Population Health and Public Health Practice

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> *Willing is not enough; we must do."*
> —Goethe

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COMMITTEE ON THE RECOMMENDED SOCIAL AND BEHAVIORAL DOMAINS AND MEASURES FOR ELECTRONIC HEALTH RECORDS

Nancy E. Adler (*Co-Chair*), Professor, Departments of Psychiatry and Pediatrics, and Director of the Center for Health and Community, University of California, San Francisco

William W. Stead (*Co-Chair*), McKesson Foundation Professor, Departments of Biomedical Informatics and Medicine, Chief Strategy Officer and Associate Vice Chancellor for Health Affairs, Vanderbilt University, Nashville, Tennessee

Kirsten Bibbins-Domingo, Professor of Medicine, Epidemiology, and Biostatistics, University of California, San Francisco, and Director, Center for Vulnerable Populations, San Francisco General Hospital

Patricia Flatley Brennan, Professor, Department of Industrial and Systems Engineering, and Professor of Nursing, University of Wisconsin, Madison

Ana Diez-Roux, Dean, Drexel University School of Public Health, Philadelphia, Pennsylvania

Christopher Forrest, Professor, Departments of Pediatrics and Health Care Management, University of Pennsylvania and Children's Hospital of Philadelphia, Pennsylvania

James S. House, Professor, Survey Research, Public Policy, and Sociology, University of Michigan, Ann Arbor

George Hripcsak, Chair, Department of Biomedical Informatics, Columbia University, and Director, Medical Informatics Services for New York–Presbyterian Hospital/Columbia Campus, New York

Mitchell H. Katz, Director, Los Angeles County Department of Health Services, California

Eric B. Larson, Executive Director and Vice President for Research, Group Health Research Institute, Seattle, Washington

Karen A. Matthews, Professor, Departments of Epidemiology, Psychology, and Psychiatry, University of Pittsburgh, Pennsylvania

David Ross, Director, Public Health Informatics Institute, Atlanta, Georgia

David R. Williams, Professor, Departments of Public Health, African and African American Studies, and Sociology, Harvard University, Boston, Massachusetts

Study Fellow

Deidra Crews, IOM Gilbert S. Omenn Anniversary Fellow and Assistant Professor of Medicine, Division of Nephrology, Johns Hopkins University, Baltimore, Maryland

IOM Staff

Karen Helsing, Study Director
Alejandra Martín, Research Associate
Emily Vollbrecht, Senior Program Assistant
Doris Romero, Financial Associate
Rose Marie Martinez, Senior Director, Board on Population Health and Public Health Practice

Reviewers

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:

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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,** Center for a Livable Future, Johns 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.

Preface

Substantial empirical evidence of the contribution of social and behavioral factors to functional status and the onset, progression, and effective treatment of disease has accumulated over the past 4 decades. Yet efforts to improve health care, advance population and public health, and develop and apply social and behavioral research remain largely separate from one another. The Patient Protection and Affordable Care Act[1] and the move toward accountable care organizations provide impetus for creating policy and business frameworks for coordinated action, with electronic health records (EHRs) as a unifying "nervous system."

This committee was charged with recommending what social and behavioral information should be included in EHRs and identifying obstacles to the inclusion of such information and ways to overcome those obstacles. The inclusion and use of such data in an EHR should foster better clinical care of individual patients and of populations and enable more informative research on the determinants of health and the effectiveness of treatments. Committee members reflecting different perspectives, disciplines, and concerns grappled with how to create a coordinated approach that would maximize the chances achieving these outcomes.

By bringing together social and behavioral scientists with clinical and public health practitioners and information technology (IT) experts, the committee forged a new understanding of different frames of thinking. Not surprisingly, the social and behavioral scientists were most focused on domains and measures that had been shown in the research literature

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[1] Public Law 111-148.

to be linked to health or longevity, while the clinicians and practitioners were more concerned with the implications of collecting the information, including how it could be used and the burden of collecting and storing it. Similarly, the committee gained an appreciation for different uses of words. For example, the terms *standard metric* and *domain* had different meaning for IT members than for social science members. During discussions, the committee often stopped to agree on definitions of the terms being used before going on to reach agreement on judgments of specific domains or measures. Readers of the report may find it helpful to read the sections that clarify the committee's use of key terms.

In its deliberations, the committee broke new ground in several ways that go beyond the usefulness of its specific findings and recommendations. This report provides a concrete approach to including social and behavioral determinants of health in the clinical context to increase clinical awareness of the patient's state, broadly considered, and to connect clinical, public health, and community resources to work in concert. The committee emphasizes the standard measures that are ready for widespread use and describe how, as a parsimonious panel, these measures can provide an initial understanding of social and behavioral determinants of health. This approach fosters interoperability as a starting point. We expanded the concept of a standard metric from a research method to a clinical approach to supporting interoperability among measures of a concept to accommodate changes over time and among populations.

Perhaps as important as the measures that the committee recommends to constitute the "psychosocial vital signs" to be gathered in all EHRs are the measures that were not included in the panel. Reflecting on the decision process calls to mind the Anna Karenina Principle, posited by Jared Diamond from the opening line of this Leo Tolstoy classic: "Happy families are all alike; every unhappy family is unhappy in their own way" (Diamond, 1994, p. 157). Diamond observes that successful programs or projects must succeed on all aspects of the undertaking, while less successful outcomes may result from any one of a multitude of problems or limitations.

The Anna Karenina Principle was demonstrated in the deliberations of our committee. The measures recommended for inclusion all scored well on all six criteria. All are standard, available measures of domains that are related to health outcomes and provide useful information, are feasible to measure, and are neither overly sensitive to ask nor available from other sources. The measures that were not recommended had specific qualities that resulted in their being given a lower priority for inclusion at this time. While the nature and extent of shortcomings varied from measure to measure, most involved gaps between the importance of domains to health and the usefulness of the associated measure for clinical care and population management. Identifying these gaps may help to guide needed research.

A number of the measures that were not included in the final panel of recommended measures had no major deficiencies. Their lack of inclusion at this time reflected the committee's belief that we needed as parsimonious a panel as possible to reduce barriers to the adoption and use of these measures. They are good candidates for inclusion by systems that want greater depth in addressing social and behavioral determinants of health and/or for inclusion in all EHRs in the next round of additions. Finally, the committee also realized that its recommendations are only a starting point. We learned of a number of current efforts to address the gaps of existing measures. While these were not far enough along to provide the kind of evidence needed to support a recommendation, some may achieve this within the next few years. Thus, the committee's final recommendation proposes a mechanism by which such advances can be evaluated and inform expansion of the core panel when justified. By expanding the number and quality of measures that can inform better, more comprehensive health care, the nation can expand the number of healthy people.

Nancy E. Adler, *Co-Chair*
William W. Stead, *Co-Chair*
Committee on the Recommended Social and Behavioral Domains and
Measures for Electronic Health Records

REFERENCE

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Many individuals generously shared their insights and expertise with the committee during the course of the deliberations leading to this report. In particular, the committee thanks Robert M. Kaplan, former director of the Office of Behavioral and Social Sciences Research at the National Institutes for Health, currently the Chief Science Officer for the Agency for Healthcare Research and Quality, for his support and vision behind this study. Further thanks go to the representatives of the sponsor agencies who addressed the committee and helped clarify its charge. These include William Riley at the National Cancer Institute, Maureen Boyle from the Substance Abuse and Mental Health Services Administration, Robert Hahn at the Centers for Disease Control and Prevention, James Marks of the Robert Wood Johnson Foundation, and Lisa and John Pritzker from The Lisa and John Pritzker Family Fund. The committee also greatly appreciates the input of speakers whose presentations informed committee thinking, including Beverly Brumfield, Michael Buck, Neil Calman, Paul Crane, Art Davidson, Richard Gershon, Alan Glaseroff, Laura Gottlieb, Shaun Grannis, Ron Hays, Robert Kahn, Kevin Larsen, Rashanda Lee, Rishi Manchanda, Brigid McCaw, David McClure, Deven McGraw, Abigail Sears, Paul Tang, Karen Tirozzi, Charlene Underwood, and William Yasnoff. Their contributions invigorated committee deliberations and enhanced the quality of this report. In particular, the committee was informed about privacy protection issues with Deven McGraw's commissioned paper, which she presented to the committee; her paper is printed in its entirety in Appendix B. We also extend our deepest thanks to Deidra Crews, the Institute of Medicine's

(IOM's) 2013–2015 Gilbert S. Omenn Anniversary Fellow, for her numerous contributions to the committee's work.

Finally, the committee acknowledges the study's multiple sponsors: the Association of State and Territorial Health Officials, the Blue Shield of California Foundation, the California HealthCare Foundation, the Centers for Disease Control and Prevention, the Centers for Medicare & Medicaid Services, the Department of Veterans Affairs, The Lisa and John Pritzker Family Fund, the National Institutes of Health, the Robert Wood Johnson Foundation, and the Substance Abuse and Mental Health Services Administration. The committee and the IOM staff thank them for their support.

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Abbreviations and Acronyms

ACA	Patient Protection and Affordable Care Act of 2010
ACES	Adverse Childhood Experiences Study
ACO	accountable care organization
AHRQ	Agency for Healthcare Research and Quality
ARRA	American Recovery and Reinvestment Act of 2009
CDC	Centers for Disease Control and Prevention
CMMI	Center for Medicare & Medicaid Innovation
CMS	Centers for Medicare & Medicaid Services
EHR	electronic health record
GEM	Grid-Enabled Measures [database]
GIS	geographic information system
HIE	health information exchange
HIPAA	Health Insurance Portability and Accountability Act of 1996
HITECH	Health Information Technology for Economic and Clinical Health Act of 2009
IOM	Institute of Medicine
IT	information technology

LGBT	lesbian, gay, bisexual, and transgender
MESA	Multi-Ethnic Study of Atherosclerosis
NCQA	National Committee for Quality Assurance
NHANES	National Health and Nutrition Examination Survey
NHIS	National Health Interview Survey
NIH	National Institutes of Health
NIOSH	National Institute for Occupational Safety and Health
NQF	National Quality Forum
OBSSR	Office of Behavioral and Social Science Research (of the National Institutes of Health)
OMB	Office of Management and Budget
ONC	Office of the National Coordinator for Health Information Technology
PCORI	Patient-Centered Outcomes Research Institute
PHQ	Patient Health Questionnaire
PROMIS	Patient Reported Outcomes Measurement Information System
PTSD	posttraumatic stress disorder
SAMHSA	Substance Abuse and Mental Health Services Administration
SBDH	social and behavioral determinants of health
SES	socioeconomic status
SNAP	Supplemental Nutrition Assistance Program
USPSTF	U.S. Preventive Services Task Force

Abstract

Despite strong evidence of the influence of social and behavioral factors on health, these factors have not been well addressed in clinical care. The increasing emphasis on population health management is focusing more attention on the social and behavioral determinants of health, but the limited availability of information on these determinants impedes efforts to delay the onset and progression of disease and improve well-being. To provide better patient care, improve population health, and enable more informative research, standardized measures of key social and behavioral determinants need to be recorded in electronic health records (EHRs) and made available to appropriate professionals.

The Committee on the Recommended Social and Behavioral Domains and Measures for Electronic Health Records was asked to recommend core measures of social and behavioral domains for inclusion in all EHRs. It identified a parsimonious panel of measures that is comprehensive, interoperable, and efficient. These "psychosocial vital signs" include four measures that are already widely collected (race/ethnicity, tobacco use, alcohol use, and residential address) and eight additional measures (education, financial resource strain, stress, depression, physical activity, social isolation, intimate partner violence, and neighborhood median household income). While recognizing the additional time needed to collect such data and act upon it, the committee concluded that the health benefits of addressing these determinants outweigh the added burden to providers, patients, and health care systems. Advances in research in the coming years will likely point to additional measures that should be included in the panel, and periodic re-reviews should be undertaken to assess them.

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, protection, and promotion 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 been of concern to health care delivery systems. A variety of pressures are increasing the need for health care systems and providers to attend to the social and behavioral determinants of health. These include the relatively poor health status of the U.S. population despite high—and possibly unsustainable—investments in health care and new incentive structures through the Patient Protection and Affordable Care Act such as accountable care organizations which reward health systems for achieving better health with less use of costly medical services.

Electronic health records (EHRs) provide valuable information about the determinants of health and the effectiveness of treatment. This information can enable more effective responses to the pressures noted above when used by health systems, including public health officials, researchers, and providers treating individual patients. Inclusion of information on social and behavioral characteristics will provide vital knowledge to inform and improve all three uses.

The Health Information Technology for Economic and Clinical Health Act of 2009 (HITECH) and the Patient Protection and Affordable Care Act 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 whether an organization can receive payments from the Medicare and/or Medicaid EHR incentive programs. 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 (HHS) 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.

Meaningful Use regulations can incentivize the inclusion of social and behavioral data in EHRs. 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 the National Institutes of Health, together with the Association of State and Territorial Health Officials, the Blue Shield of California Foundation, the California HealthCare Foundation, the Centers for Disease Control and Prevention, CMS, the Department of Veterans Affairs, The Lisa and John Pritzker Family Foundation, 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 to identify social and behavioral domains and their measures for inclusion in electronic health records. The charge to the committee for the project is presented in Box S-1.

In response to that request, the IOM convened a multidisciplinary committee of 13 members with a wide variety of expertise, including leaders from the fields of health information technology, clinical care and health systems, social and behavioral determinants of health, and measurement.

THE COMMITTEE'S APPROACH IN PHASE 1

To meet its charge, the committee first established the rationale for adding social and behavioral determinants of health into EHRs and con-

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 produce two products. As part of its work, the committee will:

Phase 1

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
4. 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

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.

sidered 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 four information-gathering meetings to hear from other experts in the field, stakeholders, and the public. In addition, the committee met in closed sessions 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-based reviews from governmental and other 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 during Phase 1 was to identify domains that should be considered by ONC for Stage 3 Meaningful Use. In this context the core domains are those that the committee proposed as candidates for being selected for Meaningful Use. The committee erred on the side of inclusion at this stage while also trying to limit the number of candidate domains. Throughout this study, the term *domain* is used to refer to determinants of health, which could include health conditions that, in turn, influence other health outcomes. The committee also embraced the use 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" (WHO, 1946).

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 (such as 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.
2. Usefulness of the domain, as measured for
    a. The individual patient for decision making between the clinician and patient for management and treatment;
    b. The population to describe and monitor population health and making 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 (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 worked to narrow the number of domains in the outline using the first two criteria through a consensus process. The result reduced the number of domains constituting the candidate set to 17 for which the committee found sufficient evidence of relevance and usefulness to consider for inclusion in all EHRs. Given the limited time that the committee had to complete its Phase 1 tasks in order for its recommendations to be useful for Meaningful Use Stage 3 deliberations, the committee only used criteria 1 and 2 to select the 17 candidate domains. Chapter 3 of the report and the criteria presented above are intended to serve as resources to support their drafts and final decisions.

Committee's Key Conclusions in Phase 1

In addition to developing criteria for selecting domains and measures to recommend for inclusion in all electronic health records, the major focus of Phase 1 was identifying a candidate set of domains relevant for all individuals. 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 encourage the use of standard measures for these domains. The domains are not listed in order of priority. Rather, they are organized by the committee's initial outline, which ordered domains in terms of types of levels they represented.

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 (Appendix A)
Sociodemographic Domains	
▪ Sexual orientation ▪ Race/ethnicity ▪ Country of origin/U.S. born or non-U.S. born ▪ Education ▪ Employment ▪ Financial resource strain (Food and housing insecurity)	▪ Gender identity
Psychological Domains	
▪ Health literacy ▪ Stress ▪ Negative mood and affect (Depression, anxiety) ▪ Psychological assets (Conscientiousness, patient engagement/activation, optimism, self-efficacy)	▪ Negative mood and affect (Hostility and anger, hopelessness) ▪ Cognitive function in late life ▪ Psychological assets (Coping, positive affect, life satisfaction)
Behavioral Domains	
▪ Dietary patterns ▪ Physical activity ▪ Tobacco use and exposure ▪ Alcohol use	▪ Abuse of other substances ▪ Sexual practices ▪ Exposure to firearms ▪ Risk-taking behaviors (Distractive driving and helmet use)
Individual-Level Social Relationships and Living Conditions Domains	
▪ Social connections and social isolation ▪ Exposure to violence	▪ Social support (Emotional, instrumental, and other) ▪ Work conditions ▪ History of incarceration ▪ Military service ▪ Community and cultural norms (Health decision making)
Neighborhoods and Communities	
▪ Neighborhood and community compositional characteristics (Socioeconomic and racial/ethnic characteristics)	▪ Neighborhood and community contextual characteristics (Air pollution, allergens, other hazardous exposures, nutritious food options, transportation, parks, open spaces, health care and social services, educational and job opportunities)

Domains Not Selected

Narrowing the initial set of domains covering the whole range of social and behavioral determinants was a difficult task. The committee's decisions were guided by awareness of the need to identify the domains for which there was adequate evidence of the association of the domains with health outcomes and of the usefulness in having the information in EHRs. Most of the domains excluded from the final candidate set simply lacked an adequate evidence base to support routine capture of these data. (See Appendix A for more information on domains not selected.) Because the Phase 1 study serves as a foundation for the committee's deliberations regarding their remaining task, the Phase 1 study report is woven into this report largely unchanged as Chapters 1–3.

PHASE 2: PRIORITIZING DOMAINS AND MEASURES

As the committee entered its Phase 2 work, two information-gathering sessions were held (see Appendix C for the agendas). The committee began to compile measurement tools for the candidate domains. These measures are essential ingredients in EHRs; they must be consistently defined and used in order to achieve interoperable standards, a priority goal for ONC. The committee also saw opportunities for increasing standardization despite logistical challenges to achieving routine, harmonized measurement tools. Toward meeting this objective, the committee applied criteria 3 through 6 to the 17 candidate domains, along with their subdomains, which had been selected as the best candidates for inclusion in EHRs, while continuing to take account of criteria 1 and 2. In several instances, multiple measures of a domain were carefully considered. In other instances, a single accepted standard measure, which had been tested for its reliability, validity, and scoring stood out. The committee weighed the usefulness and feasibility of collecting data using each measure, and potential concerns about the sensitive nature of the information or violations of privacy in collecting, storing, or using the data were also considered. Finally, the committee examined the accessibility of the data from other sources.

Initially, the committee considered each domain and measure *individually*. However, as work progressed, the committee stepped back and considered overlap between domains and their measures and interactions among them. To recommend core measures of social and behavioral domains for inclusion in all EHRs, the committee saw greater value in considering the measures as a whole and identifying a parsimonious panel of measures that would be complete, interoperable, and efficient.

The committee also considered the stability of the measure and the implications for how often they need to be assessed. Sociodemographic characteristics of the person, which help determine their resources and adverse exposures, are relatively unlikely to change, especially once one reaches adulthood. Other risk factors are more fluid. Although some health behaviors are habitual, they may fluctuate independently or in response to an intervention or treatment. Social relationships and affective states are likely to vary over time and with changing circumstances.

The stability of a domain affects the frequency with which it needs to be assessed for use in direct patient care (for screening, intervention, or monitoring), by the health system or public health, or for purposes of research. A stable domain can be assessed once at entry; others require periodic screening with detailed assessment and follow up on a positive screen. Others, such as the patient's address, require verification at every visit. Frequency of assessment is a factor in evaluating the feasibility of including a measure of the domain in EHRs; a detailed assessment may be feasible if needed only at entry, but not if needed frequently. Similarly, domains that can be assessed with a brief screen with targeted follow up are more feasible than in-depth assessments that need to be repeated.

Constructing a Parsimonious Panel of Measures: Usefulness, Readiness, and Committee Judgment

In Phase 2, evaluations of measures collapsed the four criteria into two dimensions. One dimension represents the readiness of a measure for use in the EHR. Readiness was quantified across the following criteria: availability of a standard, freely available measure; feasibility; and lack of sensitive information. The second dimension represents the usefulness of having the information generated by the measure in the patient record for clinical, population management, and research purposes. Table S-2 presents a summary of the committee's process from its identification of conceptual frameworks to its final steps in constructing a parsimonious panel of measures.

Figure 5-1 in Chapter 5 displays all the measures and where they fall on these two dimensions. The committee also assigned an overall score to each measure. In general, the strongest endorsement was for measures that scored highest on both readiness and usefulness, but some measures that were high on usefulness but somewhat lower on readiness were also included. Informed by these ratings, the committee reached consensus on four domains that are currently being collected in many clinical settings and eight domains that are not yet routinely collected. Table S-3 summarizes the 11 domains and 12 measures that compose the selected panel and the number of questions in each measure.

TABLE S-2 The Committee's Analytic Process in Narrowing Domains and Measures to a Parsimonious Measurement Panel

Process Steps	Method	Results
Conceptual Framework Analysis	Integrate models relevant to SBD of health (Figures 2-1 to 2-4)	5 Levels
Domain Identification	From extensive list of SBD concepts identified domains for consideration (Table 2-1)	31 Domains
Candidate Domains Selection	Applied criteria: strength of association with health; and clinical, population health, and research usefulness	17 Domains
Measure Identification	Domain workgroups conducted literature reviews of measures Measure set identified based on psychometric properties	17 Domains/31 Measures
Parsimonious Measurement Panel Construction	Applied criteria: readiness (standard measure, feasibility, lack of sensitive information); usefulness for inclusion in the EHR; and overall committee judgment	11 Domains/12 Measures

NOTE: EHR = electronic health record; SBD = social and behavioral determinants.

IMPLEMENTATION CHALLENGES

The need to adopt new standards and incorporate more social and behavioral information in EHRs is driven by the contrasts in the performance of the U.S. health system, which has achieved technological advances but is fragmented, uncoordinated, costly, and yielding poor population health outcomes. Implementing changes to EHRs involves not just modifications to technologies but also an expanded view of the determinants of health and adaptation in the way clinical teams work and how patients engage in their own care.

It is beyond this committee's charge to address the general challenges of EHR use. The committee was acutely aware that adding additional data to the EHR could increase the burden on health systems, clinicians, patients, vendors, as well as implementers of meaningful use regulations. Accordingly, the committee used a systematic approach to weighing the trade-offs and aimed for the most parsimonious set of measures.

TABLE S-3 Core Domains and Measures

Domain	Measure
• Race/ethnicity	• U.S. Census (2 Q)
• Education	• Educational attainment (2 Q)
• Financial resource strain	• Overall financial resource strain (1 Q)
• Stress	• Elo et al. (2003) (1 Q)
• Depression	• PHQ-2 (2 Q)
• Physical activity	• Exercise Vital Sign (2 Q)
• Tobacco use and exposure	• NHIS (2 Q)
• Alcohol use	• AUDIT-C (3 Q)
• Social connections and social isolation	• NHANES III (4 Q)
• Exposure to violence: Intimate partner violence	• HARK (4 Q)
• Neighborhood and community compositional characteristics	• Residential address • Census tract-median income

NOTE: Q = question(s).

Self-Reported Data

Most of the recommended measures rely on self-reported data. Obtaining such data does not need to add to clinicians' time as it does not necessarily need to be collected through an interview with a member of the clinical team. It can also be collected directly from the patient on paper or via a computer. Self-report can be subject to error and bias, and it is important for health care systems to help patients understand the purpose and the value of the information being collected. Future technological advances may allow collection of more objective indicators and information on experiences that individuals may not be able to remember and report reliably. For example, sensors which record data for review and upload to the EHRs if appropriate—while not without their own limitations—may eliminate or reduce the need for having to ask individuals about behaviors such as exercise or sleep.

Select measures for some determinants of health may be found in other sources related to the patient, including EHRs from other institutions; personal health records; health risk appraisals gathered by insurers, employers, or clinical data registries; community agency datasets; national surveys; and datasets gathered by third-party data integrators such as retail. Presently there are few straightforward ways to transfer data from external data sources to EHRs or vice versa.

The concept of a robust data infrastructure in a recent report, *Robust Health Data Infrastructure* (AHRQ, 2014), developed by the JASON/MITRE Corporation, offers potential in ensuring that data flows needed to make social and behavioral determinants of health accessible to the patient, to the clinical care team, to the health system, and to society are realized. Data could be stored at the point of acquisition and integrated at the point of need. With such an open architecture, the committee's recommended measures could be acquired from a wide variety of sources.

Privacy Protections

Risks to the patient in some sensitive areas, such as substance use or violence, represent considerable challenges to collecting data. However, basic safety measures are widely used. When possible, data can be de-identified to provide anonymity. For example, in syndromic surveillance the public health entity only needs to know how many cases there are—and perhaps associated information such as age, sex, and neighborhood—but the specific names of individuals are not needed. Privacy concerns are more likely in cases where there is a need to individually link EHRs to a public health registry and the data cannot be de-identified. However, the transmitted data can be encrypted.

Institutions should inform patients about the specifics of data sharing. For example, if data are being shared with public health officials, patients should be informed that this is occurring and informed of the benefits that may incur through sharing that information. Routine collection of these types of potentially sensitive data may have the additional benefit of normalizing or destigmatizing their discussion in clinical practice.

Linking Data

Linking data from EHRs to local public health departments and community agencies provides several advantages to patients, providers, and the broader community. Information can flow in both directions. For example, data in EHRs can enable public health practitioners to identify groups of persons affected by environmental pollutants and identify areas that may need environmental mitigations. Clinicians can use geocoded environmental data to coach individual patients on risk mitigation or to tailor treatment.

Public health departments or community agencies are often in the best position to address certain problems, such as food insecurity, lack of housing, and social isolation. The manner in which social and behavioral domains may be addressed falls far outside the typical interventions found in health care. For example, food insecurity may be alleviated by access to government-funded food assistance programs, but patients may need help in navigating the enrollment process, or individuals may benefit from health interventions such as group home visits, but some may also need community-level interventions.

Resource Considerations

The business model for capturing social and behavioral domains and measures in the EHR has yet to be fully realized, and few examples exist. The committee believes that cost savings will accrue from addressing the social and behavioral determinants of health. However, those bearing the costs of identifying and addressing these determinants do not necessarily benefit from the resulting savings. The benefits accrue to society, health care payers, and health systems who are reimbursed for population health management. While some of these benefits are near term, many accrue over years. The costs of adding social and behavioral domains to EHRs, such as programming, modifying workflows, and intervening on positive screens often fall on the individual health practice or hospital. The movement toward population health management and accountable care organizations may address this malalignment over time. In the meantime, costs remain a barrier.

The ultimate value of incorporating the social and behavioral domains of health in the EHR lies in engaging the patient and aligning health service and care. Such redesign is a long-term answer to facing and addressing the implementation challenges summarized here. The barriers and suggested interventions highlighted are intended to act as a reference to guide stakeholders along this journey.

LOOKING FORWARD

The inclusion of the committee's recommended measures in all EHRs (as well as those which are appropriate for specific populations) will enable:

- More effective treatment of individual patients in health care settings,
- More effective population management for health care systems and for public health agencies, and
- Discovery of the pathways that link social and behavioral factors to functioning, disease processes, and mortality that may inform new treatments and interventions.

The committee's judgments and recommendations necessarily reflect not only the *current* status of knowledge about the social and behavioral determinants of health and of the measures of the identified domains of health determinants, but also a tactical decision of the committee to put forward at this time a parsimonious initial set of social and behavioral domains and measures for inclusion in EHRs. A number of domains and measures narrowly missed inclusion in this set, and are thus readily available to be added to EHRs when the opportunity next arises. In addition, over the coming years, new research may point to the importance and usefulness of domains and measures that were not selected based on current knowledge. A number of measures are very promising and potentially important, but the committee found that they currently fell short on aspects of readiness for inclusion in all EHRs. These domains and measures that were not included in the recommended panel merit greater attention as valuable targets of research. What follows are the committee's findings and recommendations.

FINDINGS AND RECOMMENDATIONS

Finding 5-1: Four social and behavioral domains of health are already frequently collected in clinical settings. The value of this information would be increased if standard measures were used in capturing these data.

> **Recommendation 5-1: The Office of the National Coordinator for Health Information Technology and the Centers for Medicare & Medicaid Services should include in the certification and meaningful use regulations the standard measures recommended by this committee for four social and behavioral domains that are already regularly collected: race/ethnicity, tobacco use, alcohol use, and residential address.**

Finding 5-2: The addition of selected social and behavioral domains, together with the four domains that are already routinely collected, constitute a coherent panel that will provide valuable information on which to base problem identification, clinical diagnoses, treatment, outcomes assessment, and population health measurement.

> **Recommendation 5-2: The Office of the National Coordinator for Health Information Technology and the Centers for Medicare & Medicaid Services should include in the certification and meaningful use regulations addition of standard measures recommended by this committee for eight social and behavioral domains: educational attainment, financial resource strain, stress, depression, physical activity, social isolation, intimate partner violence (for women of reproductive age), and neighborhood median-household income.**

Finding 7-1: Standardized data collection and measurement are critical to facilitate use and exchange of information on social and behavioral determinants of health. Most of these data elements are experienced by an individual and are thus collected by self-report. Currently, EHR vendors and product developers lack harmonized standards to capture such domains and measures.

> **Recommendation 7-1: The Office of the National Coordinator for Health Information Technology's electronic health record certification process should be expanded to include appraisal of a vendor or product's ability to acquire, store, transmit, and download self-reported data germane to the social and behavioral determinants of health.**

Finding 7-2: The addition of social and behavioral data to EHRs will enable novel research. The impact of this research is likely to be greater if guided by federal prioritization activities.

> **Recommendation 7-2: The Office of the Director of the National Institutes of Health (NIH) should develop a plan for advancing research using social and behavioral determinants of health collected in electronic health records. The Office of Behavioral and Social Science Research should coordinate this plan, ensuring input across the many NIH institutes and centers.**

Finding 7-3: Advances in research in the coming years will likely provide new evidence of the usefulness and feasibility of collecting social and behavioral data beyond that which is now collected or which is recommended for addition by this committee. In addition, discoveries of interventions and treatments that address the social and behavioral determinants and their impact on health may point to the need for adding new domains and measures. There is no current process for making such judgments.

> **Recommendation 7-3: The Secretary of Health and Human Services should convene a task force within the next 3 years, and as needed thereafter, to review advances in the measurement of social and behavioral determinants of health and make recommendations for new standards and data elements for inclusion in electronic health records. Task force members should include representatives from the Office of the National Coordinator for Health Information Technology, the Center for Medicare & Medicaid Innovation, the Agency for Healthcare Research and Quality, the Patient-Centered Outcomes Research Institute, the National Institutes of Health, and research experts in social and behavioral science.**

With the passage of the Patient Protection and Affordable Care Act of 2010 (ACA) the United States has begun to expand health coverage to millions of uninsured Americans, and the nation is poised to reduce existing health disparities. Currently, the absence of social and behavioral determinants of health in EHRs limits the capacity of health systems to address key contributors to the onset and progression of disease. The addition and standardization of a parsimonious panel of social and behavioral measures into EHRs can help spur policy, system design, interoperability, and innovation to improve health outcomes and reduce health care costs.

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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 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 suggest that the conditions for which patients seek medical care (accounting both for access to care and the quality of the care that is received) account 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 primarily 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 records (EHRs) (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 long-term 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[1] 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

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[1] 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 quality, efficiency, and access.

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),[2] 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

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[2] Public Law 104-191, 110 Statute 1936.

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., 2014). 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., 2014). 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

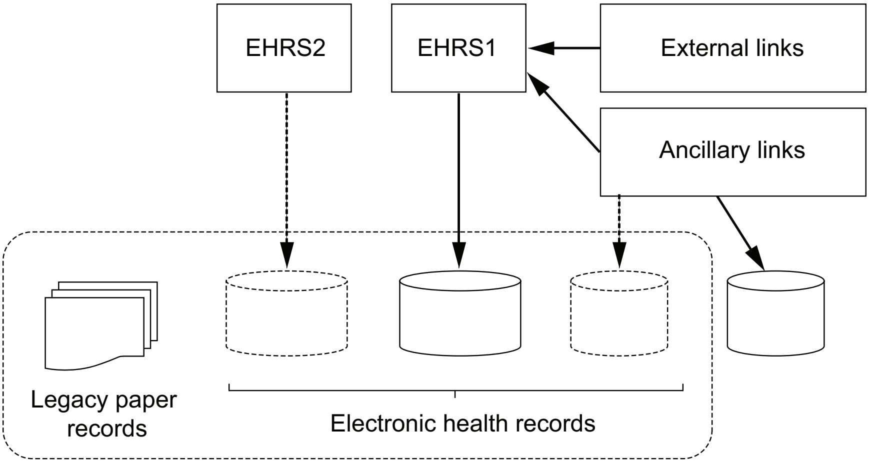

FIGURE 1-1 The legal patient record may comprise electronic and paper information from several sources. In the simplest case, a health provider may be served by a single electronic health record system (EHRS), whose database constitutes the entire legal patient record. Some organizations have more than 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, as is shown in the following sections.

Efforts to recover from the 2008 financial crisis provided an opportunity for improvement. The American Recovery and Reinvestment Act of 2009 (ARRA)[3] included the Health Information Technology for Economic and Clinical Health Act (HITECH) 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).[4]

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

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[3] Public Law 111-115.

[4] Since publication of the Phase 1 report, new data on use of EHRs point to expanded use. For example, results from the National Ambulatory Medical Care Survey, released in May 2014, revealed that in 2012 nearly 72 percent of office-based physicians used some type of EHR system. This is a significant increase from approximately 35 percent in 2007 (Hsiao et al., 2014).

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 *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 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; 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 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

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).

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 interven-

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).

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 electronic health records (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).

tions 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 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 registry-based 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, 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 these 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 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 for Health Information Technology (ONC), hears the recommendations of the Meaningful Use Workgroup, 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.[5] 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). Additionally, CMS released data at the end of April 2014 indicating that 88 percent of eligible professionals have registered for the Medicare or

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[5] Personal communication, G. Hripcsak, Colombia University, October 21, 2013.

Medicaid EHR incentive programs. Seventy percent of these professionals completed requirements and received incentive payments. Ninety-five percent of eligible hospitals had registered, with 91 percent completing Stage 1 requirements (ONC, 2014). Although progress continues, few providers and hospitals have completed adoption of Stage 2 (HealthIT.gov, 2014). Of particular relevance to our task, currently only 41 percent of hospitals are able to send and receive messages to organizations outside the hospital system regarding patient information, creating gaps in the potential for outside linkages to other public health resources (HealthIT.gov, 2014).

April 2014 also saw the release of the report by the JASON/MITRE Corporation, *A Robust Health Data Infrastructure,* which noted that "the current lack of interoperability among the data resources for EHRs is a major impediment to the unencumbered exchange of health information and the development of a robust health data infrastructure" (AHRQ, 2014, pp. 5–6). The report is referenced in Chapter 6 of this report.[6]

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 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

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[6] This text has been revised since the release of the Phase 1 report.

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).[7]

CHARGE TO THE COMMITTEE

With the National Institutes of Health at the helm, a collaboration among the Association of State and Territorial Health Officials, the Blue Shield of California Foundation, the California HealthCare Foundation, the 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 D for the biographical sketches of the committee members.)

This study was 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 in Phase 1, 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 during Phase 1 in order to clarify its statement of task; learn about meaningful use objectives; and hear from other

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[7] ONC's Meaningful Use Workgroups were being restructured over the summer of 2014, and in July 2014, the HIT Policy Workgroup released its recommendations for Stage 3 Meaningful Use to ONC (Health IT Policy Committee, 2014). At the time of publication, it was unclear when ONC will be moving these recommendations forward to CMS and if and when CMS would accept them or request additional work for ONC on Stage 3 requirements.

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
4. 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.

experts in the field, stakeholders, and the public on domains that the committee should consider. (See the meeting agendas in Appendix C.) 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 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 further winnowed the list of candidate domains to a smaller number of recommended "core" domains during Phase 2. 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 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 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 in Box 1-5.

The study was limited by the need to keep a very tight timeline for preparation and publication of the Phase 1 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 deter-

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).

mined 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, the 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).

Prior to the release of its Phase 1 report on April 8, 2014, the committee began to address its task for Phase 2. In fact, while its Phase 1 report was being reviewed by independent experts (see page vii), the committee held its third public meeting. Its purpose was to learn from invited experts about measurement of social and behavioral determinants of health and successful implementation strategies for including measures of the domains in EHRs. A fourth public meeting was held that April to present the Phase 1 report to interested participants and receive feedback on the report. The meeting also allowed the committee to hear from speakers about the best ways to collect information, successes and challenges in linking EHR data between public health departments and other relevant organizations, and how systems can be developed in which data flow freely among all relevant users. A key component was learning about patient privacy protection issues in adding potentially sensitive social and behavioral data elements into EHRs. Finally, a panel of speakers addressed obstacles in adding measures to EHRs and suggested ways to overcome these barriers for the patient, provider, system, and society. Following each information-gathering meeting, the committee met in closed session for discussion and deliberation.

ORGANIZATION OF THE REPORT

This report is a synthesis of Phase 1 and Phase 2 of the study. The Phase 1 report, woven into this report largely unchanged as Chapters 1–3, 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.

During the course of its Phase 2 work, the committee did make a few edits for clarification. For example, the domain name Tobacco Use and Exposure was more descriptive of the evidence reviewed for that domain than was the name Nicotine Use and Exposure. Accordingly, the name of the domain was changed throughout the report.

The material added during Phase 2 starts with Chapter 4, which details the measures for each domain that the committee reviewed. Chapter 5 considers the measures relative to one another on the basis of usefulness, readiness, and the committee's overall judgment, and the committee recommends a parsimonious panel of measures for inclusion in all EHRs. Chapter 6 details challenges and opportunities in adding new data to EHRs, including addressing patient privacy issues, and examples are provided of how data can be shared with local public health departments and community agencies. Chapter 7 identifies the opportunities and challenges engendered by the adoption of the recommended panel of measures in all EHRs, including implications for future research. It also identifies the need for ongoing assessment and processes to consider adding additional measures as they become ready for inclusion in EHRs. A preface is included in this report, written by the committee co-chairs. Appendix A includes descriptions of all of the domains reviewed and not selected by the committee, and Appendix B contains a commissioned paper authored by an independent consultant to the committee. Appendix C includes the meeting agendas, and the committee member biographies are available in Appendix D.

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2

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 an 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 health-related 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).

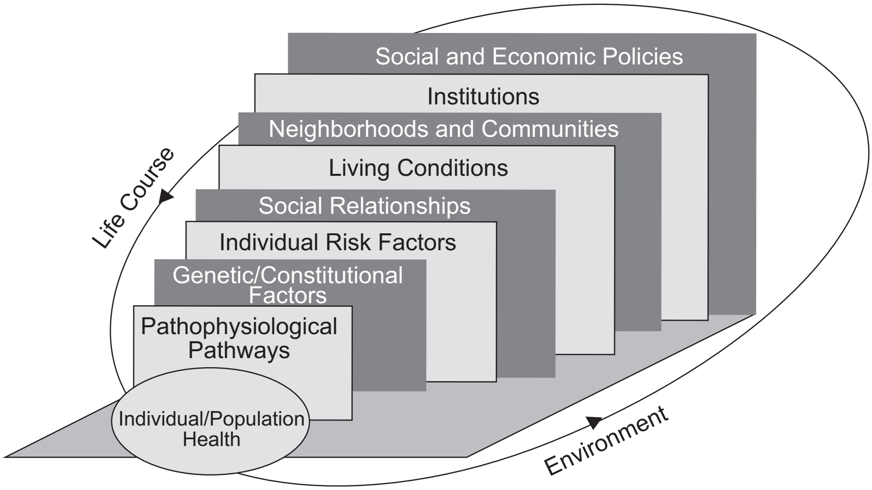

FIGURE 2-1 Multilevel approach to epidemiology, 2000. The approach of Kaplan et al. (2000) attempts to bridge various levels of explanation and intervention, bringing together theory and empirical work that link observations of causal influence and mechanism at multiple levels.
SOURCE: IOM, 2000a.

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

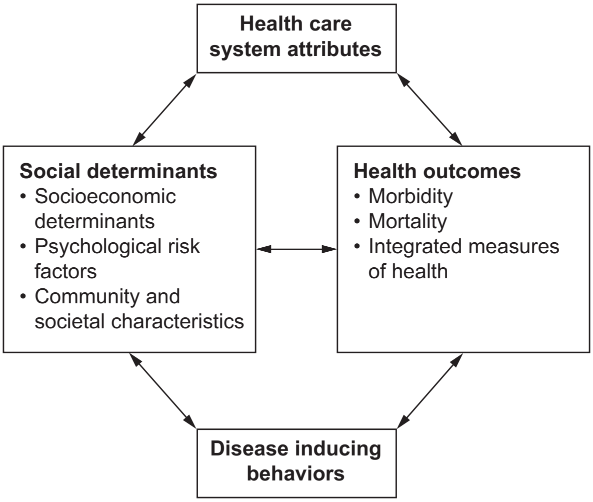

FIGURE 2-2 Categorizations of social determinants of health. The approach to Ansari et al. (2003) illustrates how social determinants of health are usually put into four categories (health care system attributes, social determinants, health outcomes, and disease inducing behaviors) and the relationship among them.
SOURCE: Reprinted with kind permission from Springer Science + Business Media: Soz Präventivmed, 2003, Ansari et al., Figure 1.

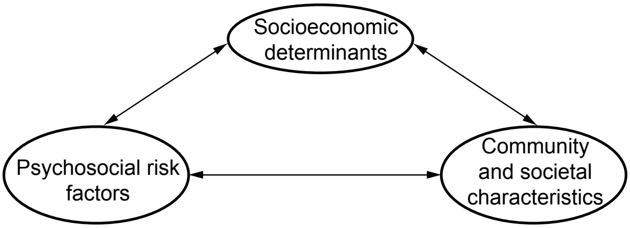

FIGURE 2-3 The public health model of social determinants of health. Approach of Ansari et al. (2003) used to diagram the interrelationship of the components of social determinants (socioeconomics, psychosocial risk factors, and community and societal characteristics) by use of a public health model of the social determinants of health.
SOURCE: Reprinted with kind permission from Springer Science + Business Media: Soz Präventivmed, 2003, Ansari et al., Figure 2.

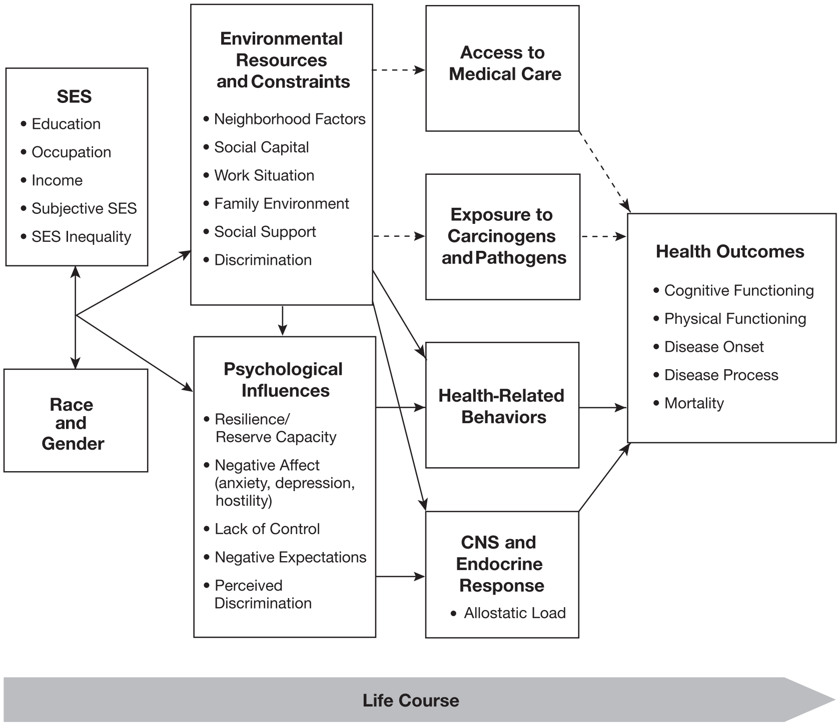

FIGURE 2-4 Pathways linking socioeconomic status and health. The solid lines indicate the pathways studied by the MacArthur Research Network on Socioeconomic Status and Health, and the dashed lines indicate pathways of importance that the network did not study.
NOTE: CNS = central nervous system; SES = socioeconomic status.
SOURCE: Adler and Stewart, 2010, Figure 3.

committee used the term *health system* as the broadest term that includes all organizations that are devoted to maintaining and improving health. This encompasses both the "health *care* system" and public health.[1] The 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

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[1] In Phase 2, the committee added the definition for health system to clarify the term to include the health care system and public health.

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 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 patient-reported 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.[2]
2. Usefulness of the domain as measured for

    a. The individual patient for decision making between the clinician and patient for management and treatment;[3]
    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.

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[2] 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" (WHO, 1948). This definition was not originally included in the committee's Phase 1 report.

[3] 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.

TABLE 2-1 All Domains Committee Considered

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

Psychological	**History of Incarceration**
Literacy/Health Literacy	**Military Service**
Stress	**Stress**
Negative Mood and Affect	
Hostility and anger	**Social Norms/Culture—health decision making**
Depression	
Anxiety	
Hopelessness	
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 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 Phase 2 report has been updated to correct the errors.

TABLE 2-2 Health Information Surveys and Technologies

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

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).

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 10 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 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. When evaluating the usefulness of systematically including a measure of the domain in terms of its value in every EHR to the individual patient, the committee narrowed its focus to the intersection of health and health care. To further the committee's work in its subsequent chapters, criteria 3 through 6 will be applied in reviewing domain measures and 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 the Phase 1 report because existing measures had not been compiled for the 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 example of neighborhood and community compositional characteristics, described later in the text, has 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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3

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 tobacco 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 Chapters 6 and 7. 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 Chaper 4 and these measures may be tailored to specific populations, as guided by use of the life course perspective.

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 an intimate partner, and higher rates of some diseases such as depression and autoimmune 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 through 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 autoimmune 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 higher 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.

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; IOM, 2013b). 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 domain (a) in 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. Chapters 4 and 5 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 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,[1] optimism, and self-efficacy

Behavioral Domains
- Dietary patterns
- Physical activity
- Tobacco use and exposure[2]
- Alcohol use

Individual-Level Social Relationships and Living Conditions Domains
- Social connections and social isolation
- Exposure to violence

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[1] The Phase 1 report had several editorial errors in the labeling of domains/subdomains. The report has been updated to correct the errors.

[2] 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[3]
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, and bisexual 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 lesbian, gay, bisexual, and transgender (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 among 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

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[3] 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.

as being 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 to 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 (i.e., programs different from those for heterosexuals), the recommendation to individualize substance treatment requires understanding the life circumstances of lesbians, gays, and bisexual persons (Green and Feinstein, 2012). In addition, negative attitudes about homosexuality can make it difficult for lesbian, gay, and bisexual 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 of disclosing sensitive information electronically. Additionally, health care providers may have inadequate training to treat lesbian, gay, and bisexual 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 lesbian, gay, and bisexual 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 lesbian, gay, and bisexual people have unique health experiences and needs (IOM, 2011a). The availability of information on an individual's sexual orientation would allow researchers to obtain more specific information on the experiences and needs of the members of the lesbian, gay, and bisexual population, especially of specific subgroups of lesbian, gay, and bisexual individuals, rather than all lesbian, gay, and bisexual individuals as a single homogenous group. To advance understanding of the health needs of all lesbian, gay, and bisexual 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 lesbian, gay, and bisexual 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 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 patient's 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 Collins, 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 populations. In addition, improvements in health equity resulting from the Patient Protection and Affordable Care Act,[4] which has a number

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[4] Public Law 111-148.

of 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 but also, 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 (CDC, 2012b). 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 who are admissible but 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 (i.e., 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 identification 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. 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. However, 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, case-controlled, 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 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, a community, or a 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 the 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 an 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 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 the 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.[5] Financial resource strain is also influenced by the characteristics of the com-

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[5] 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 women, employment 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 is 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 literacy, 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 systems-based 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 relevant 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 can 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 the 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 a lifetime 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 information 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.[6] 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 Engagement/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 engagement/

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[6] Public Law 111-148.

activation. 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 engagement/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 industriousness were the facets most related to conscientiousness across health behaviors.

Patient engagement/activation Most of the research linking patient engagement/activation, participation in care, and clinical outcomes has been published in the past 5 years. Evidence of the association of patient engagement/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 engagement/activation, and health literacy, these concepts exert distinct effects on patient participation in care and subsequent health outcomes (Smith et al., 2013).

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).

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 engagement/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) reveals 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 problem-solving 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 per 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 fast-food outlets at least once per 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 was 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, who 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 did 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 moderate-intensity 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 for boys (Dumith et al., 2011). This transition continues into adolescence 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) women engage in as children and in early adulthood that increases their bone mass protects 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 per 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. Tobacco 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 ages 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 smoke, whereas 9.7 percent of pregnant women who 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 a 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 tobacco use beginning in adolescence and young adulthood and 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' tobacco 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' tobacco 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 communities 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 per week for men, and no more than 7 drinks per 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 is 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).[7] 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 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-year-olds 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) estimate 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. The same study

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[7] The prepublication version of the Phase 1 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.

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 ages 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's 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 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 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 an additive relationship or in a buffering or an 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 his or her 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 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 that 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 specific populations who may require more intensive screening.

Evidence of Association with Health

Exposure to and the experience of violence have near-term and far-reaching 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 depression, 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 short- and 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 because 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. Gender-based 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 whether their patients are being exposed to or experiencing violence, they can create a comfortable space for their patients 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. There is no evidence that screening to identify women at risk leads to increased risk, although concerns about screening mothers in front of children exist. 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.

Neighborhood and Community 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 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 level, and they 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, and 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 socioeconomic composition 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 have information on the neighborhood socioeconomic composition 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 socioeconomic 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 socioeconomic composition 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 the candidate domains identified favor individual capacities and characteristics rather than social level issues, this reflects that data reported by individual patients are 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 socioeconomic composition, 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 next chapter will be to identify measures under each domain specified in this chapter. 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 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 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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4

Measures Reviewed for Each Candidate Domain

The chapters that follow move beyond addressing the Phase 1 objectives to its Phase 2 objectives, as per its Statement of Task, Box 1-4. This chapter's primary focus is on measurement tools for the committee's candidate domains—essential ingredients in electronic health records (EHRs) that must be consistently defined and used in order for our health system to assess and to achieve quality health outcomes. Having identified relevant domains in relation to their importance to health and the usefulness of having information on the domain for improving health, the committee turned to reviewing the availability of appropriate measures for each domain. Even if a domain is strongly linked to health and would inform individual or population health or research on health and health care, it could be problematic to include in the EHR without measures that meet the four criteria set by the committee in relation to the measure (see Box 4-1 for the criteria used in selecting measures). The proliferation of measurement sets and reporting requirements can place a burden on both patients and clinical teams. The logistical challenges for routine, harmonized measurement tools are significant, but as described in earlier chapters, opportunities exist toward increasing standardization. Toward meeting this goal, the committee applied criteria 3 to 6 to the 17 candidate domains, along with their subdomains, in reviewing and evaluating measures of those domains. The criteria are identified in Chapter 2 and listed below in Box 4-1.

In this chapter the committee provides definitions for measures and metrics for these domains and discusses the measures it reviewed. The committee did not have time or resources to provide extensive descriptions for all of the measures that exist relevant to each domain. In several instances,

BOX 4-1
Criteria Used for Selecting Core Domains and Their Measures as Part of Phase 2

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 (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).

there was a single accepted measure, which had been tested for its reliability, validity, and scoring. In others, multiple measures of a domain were considered if no single measure stood out.

The committee conducted literature searches to collect measurement tools and questions used domestically and internationally for the candidate domains. It relied on peer-reviewed literature in these efforts as well as for identifying a clear and consistent purpose for each measure. The committee considered the usefulness and feasibility of collecting data, the needed frequency of collecting this data, and privacy concerns or other sensitive issues that may exist for collection of those data in EHRs. The committee used its criteria to judge whether patients would consider a question or instrument to be sensitive or if it requested personal information that they may be reluctant to disclose. Privacy issues in collecting and sharing health data are discussed in more detail in a commissioned paper the committee used to inform their decisions. The paper is located in Appendix B of this report.

Finally, the committee examined the accessibility of the data from other sources. Data that are consistently collected externally would have a lower priority for being collected in the EHR. However, linkages between data collected in surveys, such as in the U.S. Census, currently cannot be smoothly integrated into an individual EHR.

MEASUREMENT TERMS

For this report, *domains* refer to behavioral or social determinants of current or future health outcomes. In the social and behavioral sciences, domains are often called *constructs*, because they are attributes that cannot be measured directly. The *operational definition* of a *domain* or construct describes the operations that are used to assess it, which generally involve *measurement* tools that enable assigning numbers to (social or behavioral) attributes according to rules (Stevens, 1946). Subdomains are dimensions within a domain, each with its own operational definition and measurement tools.

Some constructs can be directly measured. For example, body mass is a function of height and weight. Both are observable variables that can be directly measured using instruments, such as a stadiometer or scale, respectively. Operational definitions of other domains involve asking individuals to respond to structured questions that can yield a numerical value that indicates the presence or absence or extent of the construct. Depressive symptoms or social support are examples of constructs that are assessed through responses to questions. See Box 4-2 for information on instruments and scales.

If measurements of social and behavioral attributes are to be collected in EHRs, they should be recorded in ways that enable *interoperability* across time and between electronic health record systems. For interoperability to succeed, the data that are intended to measure a given domain must have the same meaning across data sources and be able to be combined. For example, weight is conventionally represented on the kilogram scale. If, however, one dataset represented weight as pounds and the other as kilograms, the data could not be combined without transformation from one scale to the other, because of nonequivalence of the meaning of the numerals used to represent the domain of weight. A 2011 Institute of Medicine report *For the Public's Health: The Role of Measurement in Action and Accountability* noted that because data elements are not standardized, individual decision makers base their choices on different information (IOM, 2011b).

By *metric* the committee is referring to the underlying data structure and scale for any measurement, including social or behavioral variables. A metric is agnostic to the specific instrument used to obtain the data. However, it does specify the properties of the scale on which the measurements of the variable that represents the domain will be expressed. The metric clearly defines the structure of the variable in the dataset and the meaning of the numerical representations of different categories or levels of the variable. A single metric in theory could have numerous instruments all of which provide measurements that are represented on the same standard

BOX 4-2
Use of Instruments and Scales

Instruments are tools or procedures used to obtain measurements of a domain. The data produced by an instrument can be represented on four types of scales that differ by their mathematical properties. These include nominal, ordinal, interval, and ratio scales. A *nominal scale* assigns numbers to categories that have no logical ordering. There is a one-to-one correspondence between a category and its numeric representation. For example, gender and race/ethnicity are measured on a nominal scale, and a single numeral is used to represent each gender and race/ethnicity category. An *ordinal scale* rank-orders categories such that increasing numbers mean more of some attribute, and vice versa. An example would be a zero to ten pain scale with increasing ratings connoting higher levels of pain. In an ordinal scale the difference between a score of 6 versus 5 is not necessarily equivalent to 10 versus 9. The numbers of an ordinal scale merely indicate more or less of an attribute. An *interval scale* reflects rank-ordered categories like an ordinal scale, but the differences between numerals are known to be equal. Two interval scales of the same attribute would be linear transformations of one another, such as the Celsius and Fahrenheit scales of temperature. (Most behavioral and social domains are measured on a scale somewhere between ordinal and interval. In such scales, the differences between values may be equivalent across most levels of the variable, but equality of differences may not hold for the full range of values, such as at the tails of the distributions.) A *ratio scale* refers to equality of ratios, and has a natural zero point. Doses of a given medicine can be used as an example that would be measured on a ratio scale. There is a logical zero point (e.g., no medication) and an equivalent ratio scale of two doses have the same interpretation (e.g., a 10-milligram dose is twice the amount of a 5-milligram dose).

scale. For example, if the metric for weight is the kilogram scale, the *instrument* used to obtain weight could be patient self-report or observed and reported on by the clinical team based on a physical weighing scale. In both cases, the measurement can be recorded on the same kilogram scale, but the measurement error associated with self-reports may be higher.

The relationship between the domain concept, its subdomains, the metrics, and instruments that provide measurements on the common metric is shown in Figure 4-1. For example, the domain of physical activity has several subdomains (mobility/motion, flexibility, and strength) and various ways of expressing it. The committee chose a metric of metabolic equivalent of task (MET)-minutes to represent the mobility/motion subdomain of physical activity. MET-minutes may be obtained by asking individuals to recall the frequency, intensity, and type of physical activities they have engaged in over a specified prior interval; a multitude of self-reported instruments could be used for this purpose. Alternatively, MET-minutes could be derived from a device called an accelerometer. (See section below on physical activity for more information on accelerometers.) Interoperability is achieved if all the instruments can be represented electronically as the same metric, that is, MET-minutes. This example also illustrates the importance of specifying the metadata associated with how the data were collected and which instrument was used.

The committee used the following process to evaluate the suitability of the measures of each of the candidate domains for inclusion in all EHRs or for special populations. First, a committee member with expertise in the domain identified available measures for the domain or subdomains. She or he summarized the extent to which a measure met the additional considerations set by the committee for adequacy of measures: availability of standard measures and instruments free from intellectual property restrictions; reliability and validity of those measures; feasibility of collecting the data required by the measure; sensitive information or patient discomfort in the information reported; and the potential benefit and risk of including the measure in EHRs. In some instances, the committee chose to use one or two questions from a full set of validated questions. They did this in order to make the domain measures feasible in a clinical setting. In

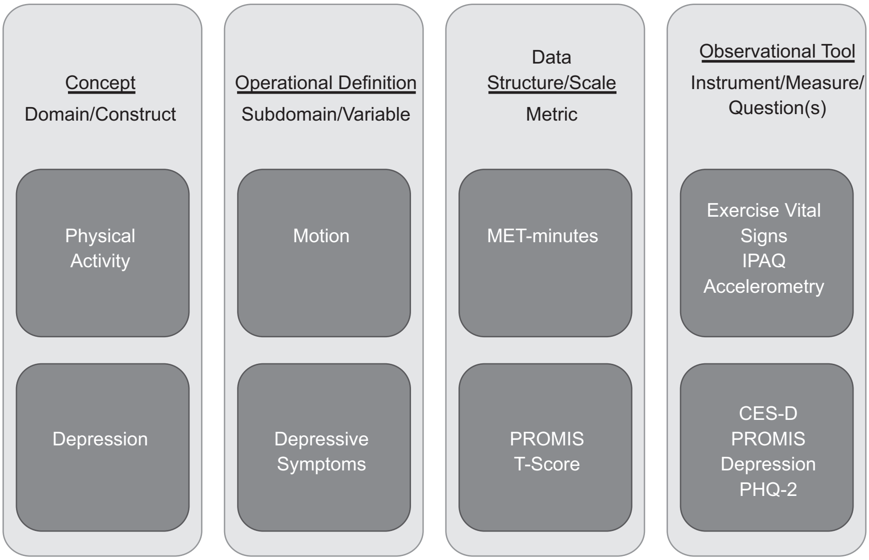

FIGURE 4-1 Examples of domains, subdomains, metrics, and instruments.

general, individual questions have already been tested prior to using them as a question set.

The committee combined information regarding the six considerations described above into a rating on four criteria: standard measure, usefulness, feasibility, and if the measure includes sensitive information or causes patient discomfort. Usefulness was defined as the usefulness of systematic incorporation of the standard measure in all EHRs, which includes broad applicability and utility in the clinical setting. Committee members individually assigned from one to three stars to each measure for each criterion, where three was best. Following committee discussion, a consensus judgment was reached on these ratings, and a rating of the overall committee judgment of the priority of including the measure in all EHRs was determined. The small table for each measure summarizes these ratings.

In the sections that follow, the committee describes examples of possible measures for each of the candidate domains listed in Chapter 3 and repeated below. As in Chapter 3, the domains are not listed in order of priority, but follow the committee's initial classification and outline of the domains into five levels (sociodemographic, psychological, behavioral, individual-level social relationships and living conditions, and neighborhoods and communities) in Chapter 2.

Sociodemographic Domain Measures

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 Domain Measures

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

Behavioral Domain Measures

Dietary patterns
Physical activity
Tobacco use and exposure
Alcohol use

Individual-Level Social Relationships and Living Conditions Domain Measures

Social connections and social isolation
Exposure to violence

Neighborhoods and Communities Domain Measures

Neighborhood and community compositional characteristics

SOCIODEMOGRAPHIC DOMAIN MEASURES

Candidate sociodemographic domains include domains described in the Kaplan and colleagues' (2000) epidemiological model and the Ansari and colleagues' (2003) public health model for describing the interactions, pathways, and causalities between social and behavioral determinants of health and health outcomes, such as individual factors (e.g., country of origin, sexual orientation, education, and employment), social factors (e.g., race, ethnicity, sexual orientation), and living conditions (e.g., financial resource strain). In the Ansari model, most of these domains would fall under socioeconomic determinants. The committee notes, however, that some domains may span across levels. For example, race, ethnicity, and sexual orientation are individual factors that are affected by social and cultural factors.

Sexual Orientation

Sexual orientation is characterized by two separate but related subdomains: self-identification and choice of partner for having sex. Self-identification—how people define their sexual orientation—can differ from their actual behavior. For example, an individual may define her- or himself as heterosexual (or gay or bisexual), yet not actually have sex with anyone. Another individual might define her- or himself as heterosexual yet have sex with others of the same gender.

Identification and Description of Measures

Two standard questions with standard responses have been used in multiple surveys to measure sexual orientation: one question for self-identification and another for sexual behavior. For example, the California Health Interview Survey (CHIS) has asked California residents about their sexual orientation by asking two questions (CHIS, no date). The question for sexual behavior asks the respondents about the gender of their sexual partner(s):

> In the past 12 months, have your sexual partners been male, female, or both male and female?

The question for self-identification is:

> Do you think of yourself as straight or heterosexual, as gay (lesbian) or homosexual, or bisexual?

During the CHIS interview, interviewers are prompted to further explain to the respondent what is meant by the self-identification question by saying (CHIS, no date):

> Straight or heterosexual people have sex with, or are primarily attracted to people of the opposite sex, Gay (and Lesbian) people have sex with or are primarily attractive to people of the same sex, and Bisexuals have sex with or are attracted to people of both sexes.

The committee believes that more detailed questions about sexual practices are better asked as part of the clinical interview.

Common Metric

There is not a commonly accepted metric for these measures at this time.

Ratings of Measures by Committee

The two questions listed in the above section are both publicly available with no licensing restrictions for use. Knowledge of a person's self-identified sexual orientation and sexual behavior can be useful for diagnosing and treating conditions that may be related to sexual orientation—for example, African American gay, bisexual, and men who have sex with men represented an estimated 72 percent (10,600) of new HIV infections among all African American men and 36 percent of an estimated 29,800 new HIV infections among all gay and bisexual men (CDC, 2014b). For most conditions, however, knowing this would not change the clinical approach. Because of this, the committee judged that it is not highly useful to systematically include these measures in all electronic health records.

Both questions could be feasibly asked without putting much burden on the patient or clinical workflow. The CHIS reports that the refusals to answer these questions are no greater than that of other questions on the survey (CHIS, 2014). However, asking questions about sexual orientation can be highly sensitive, including for people who think that their sexual orientation or sexual behaviors are private matters and should not be asked unless they are directly relevant for their current medical care. Based on these considerations, the committee rated the measure as follows in Table 4-1.

Limitations of Measures

Some individuals may not want to answer questions related to sexual orientation because they feel it is not relevant to their medical care. The questions do not enable a clinician to determine what potential screening a patient needs for sexually transmitted diseases without asking additional questions concerning specific sexual behaviors.

Specific Populations

Adolescence can be a particularly challenging time for teens who think they may be gay or lesbian. Gay and lesbian teens have a higher rate of mental distress and suicidality than their "straight" peers. Their sexual preferences are still being formed and, no matter what their self-identification, they may have not had sex with anyone, or they may have only had sex with persons of the other sex. They may not want their parents or their friends to know about their sexual feelings or activities. For teenagers, the committee believes questions about sexual orientation should be asked starting at 13 years of age, which is the age at which pediatricians start to separate children from their parents during the examination. The questions should be asked by the clinician in the examination or consultation room, not on a paper form to be handed to a registration clerk.

Other Measures Reviewed

There are other commonly used measures (to whom a person is attracted regardless of how they identify themselves or who they have sex with), but these questions appear to be less critical for medical care. A panel, Sexual Minority Assessment Research Team (SMART), was formed by the Ford Foundation to determine the "best scientific approaches to gathering data on sexual orientation" (SMART, 2009). SMART recommends three questions: one for self-identification, one for sexual behavior, and one for sexual attraction. (See the SMART, 2009, report for more information.) The self-identification and sexual behavior questions are the same as the ones identified by the committee. The committee viewed the sexual attraction question to be less clinically relevant to health than the other two questions. Fenway Health, a group practice in Boston with a large population of lesbian, gay, bisexual, and transgender individuals has begun measuring

TABLE 4-1 Ratings of the Measures on Sexual Orientation

Domain Measure	Standard Measure and Freely Available (*** = standard, * = no standard)	Usefulness (*** = most useful, * = least useful)	Feasible (*** = most feasible, * = least feasible)	Lack of Sensitive Information or Patient Discomfort (*** = least sensitive, * = most sensitive)	Committee Judgment of the Measure (*** = highest rating, * = lowest rating)
Self-Identification	***	*	***	**	**
Sexual Behavior	***	**	***	*	**

sexual orientation and gender identity using a paper registration form. A study conducted by the Fenway Institute on four community health centers found acceptability and feasibility of asking three questions—one on sexual orientation and two on gender identity—as part of patient registration (Fenway Institute and Center for American Progress, 2013). The question on sexual orientation is similar to the question reviewed by the committee on sexual identity. The other two questions ask about gender identity, which is a domain the committee considered and reviewed but did not select as a candidate domain.

Race and Ethnicity

Measures of race and ethnicity are commonly included in EHRs; however, the method of ascertainment (i.e., patient self-report versus clinical staff determination based solely on patient appearance) and the metrics (i.e., the specific racial categories available for selection) vary considerably.

Identification and Description of Measures

The Office of Management and Budget (OMB) defines the standards for the classification of federal data on race and ethnicity (OMH, 2010). In 1997, the OMB announced revisions to the Standards for the Classification of Federal Data on Race and Ethnicity. The current standards have five categories for race (American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, and White) and two categories for ethnicity (Hispanic or Latino and Not Hispanic or Latino). When race and ethnicity are collected separately, the number of White and Black persons who are Hispanic must be identifiable, and capable of being reported in that category. If a combined format is used to collect racial and ethnic data, the minimum acceptable categories are American Indian or Alaskan Native; Asian or Pacific Islander; Black, not of Hispanic origin; Hispanic; and White (OMB, 2003). Currently, Meaningful Use Stage 2 is using OMB's categories of race and ethnicity and is in the process of reviewing added categories similar to the U.S. Census.

The U.S. Census has been collecting information on race, in some form, since the late 1700s (U.S. Census Bureau, 2014b). Throughout the decades, many changes and adaptations resulted in the adding of race and ethnic categories. As of 2010, the U.S. Census uses one unique category for collecting information on ethnicity, which is whether the person is of Hispanic, Latino, or Spanish origin. If the answer is yes, then four options are given for describing this background, including an option to write in information (PRB, 2009). Multiple ethnic origins may be selected. For race, the U.S. Census lists 15 possible options. This question also includes the option to write in a tribe for persons of American Indian or Alaska Native race, and allows written specification of Other Asian and Other Pacific Islander. An option to write in some other race is also provided, as is the option to select multiple races. The following are the two questions on race and ethnicity (PRB, 2009)[1]:

Question 5: Is the person of Hispanic, Latino, or Spanish origin?
- ☐ No, not Hispanic, Latino, or Spanish origin
- ☐ Yes, Mexican, Mexican American, Chicano
- ☐ Yes, Puerto Rican
- ☐ Yes, Cuban
- ☐ Yes, another Hispanic, Latino, or Spanish origin (with fill in option)

Question 6: What is the person's race? Mark one or more races to indicate what this person considers himself/herself to be.
- ☐ White
- ☐ Black, African American, or Negro
- ☐ American Indian or Alaskan Native (with fill in option)
- ☐ Asian Indian
- ☐ Chinese
- ☐ Filipino
- ☐ Japanese
- ☐ Korean
- ☐ Vietnamese
- ☐ Native Hawaiian
- ☐ Guamanian or Chamorro
- ☐ Samoan
- ☐ Other Pacific Islander (with fill in option)
- ☐ Other Asian (with fill in option)
- ☐ Some other race (with fill in option*)*

Common Metric

The U.S. Census 2010 questions 5 and 6 are detailed metrics of race and ethnicity used at the federal level for assessing the demographic composition of the United States.

Ratings of Measures by Committee

The OMB racial and ethnic group measures provide a minimum set of categories, while the U.S. Census items provide a more comprehensive

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[1] The 2010 Census questionnaire was mailed to every household in the United States with directions indicating that the person who filled out the form would be identified as Person 1. Person 1 was also asked to answer questions about every household member, including identifying race and ethnicity (PRB, 2009). These two questions will need to be adapted accordingly for patient self-reporting for use in EHRs.

and specific description of race and ethnicity. The U.S. Census race and ethnicity questions will be useful for health care providers to determine which patients to screen for certain conditions (based on the epidemiology of those conditions across race and ethnic groups) and will help identify populations for which cultural competency training may be warranted for clinical staff. Additionally, the U.S. Census questions allow health systems to track patient outcomes across multiple racial and ethnic origins and are easily comparable to national data on the same groups. These measures are highly feasible to collect, and should be self-reported rather than determined by clinical staff. Because of these considerations the committee rated the measures of the race/ethnicity domain as follows in Table 4-2.

Limitations of Measure

Limitations of the U.S. Census questions include the time and financial costs to operationalize these detailed metrics (i.e., entering write-in categories into the EHR).

Specific Populations

Children and adolescents may find self-reporting their racial and ethnic identity to be challenging. The committee recommends that race/ethnicity be ascertained from parents of children and adolescents up to age 18 years. Older adolescents may be able to validly report their race/ethnic identity; however, further qualitative research is needed to identify the specific age at which youth can validly self-report this personal characteristic.

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

The United States is composed mostly of immigrants, some more recent and others from prior generations. As a health-related domain, immigration is a complex concept with several subdomains—including country of origin, years since immigration, immigration status, acculturation, primary language, preferred language for health care encounter, literacy, race, and ethnicity—all of which in varying degrees impact health. Being native or foreign-born and degree of acculturation have implications for health. First-generation immigrants tend to have better health outcomes than acculturated and U.S. born second or later generational individuals (Singh and Miller, 2004). For example, immigrant Latinos are less likely to be depressed and anxious, have lower cancer and cardiovascular rates, and have better infant birth weight than do U.S. born Latinos (Franzini et al., 2001; Lara et al., 2005).

TABLE 4-2 Ratings of the Measures on Race and Ethnicity

Domain Measure	Standard Measure and Freely Available) (*** = standard, * = no standard)	Usefulness (*** = most useful, * = least useful)	Feasible (*** = most feasible, * = least feasible)	Lack of Sensitive Information or Patient Discomfort (*** = least sensitive, * = most sensitive)	Committee Judgment of the Measure (*** = highest rating, * = lowest rating)
U.S. Census: Race/ Ethnicity	***	***	***	***	***
OMB Definition	***	**	***	***	***

Identification and Description of Measure

Country of origin and length of time in the United States are relatively straightforward variables to collect as exemplified by questions included in the U.S. Census. Acculturation is a more complex concept for which there is no universally accepted "gold standard." However, researchers frequently use proxy measures for acculturation that involve single items or composite variables based on questions relating to the following: country of origin, time spent in the United States, generation in the United States (via country of origin of parents/caregivers), and language used in medical appointments and/or most frequently used in the home. Language is thought to be the strongest single predictor of acculturation (Alegria, 2009; Arcia et al., 2001; Marin and Gamba, 1996). Most of the literature base for acculturation measures is derived from studies among Latinos migrating to the United States.

In addition to country of origin, there are additional measures from the U.S. Census Bureau's long-form questions that can be used. (Below are the questions if read orally):

11a. Does this person speak a language other than English at Home?
  ☐ Yes
  ☐ No → skip to question 12
11b. What is this language? (Fill in information)
11c. How well does this person speak English?
  ☐ Very well
  ☐ Well
  ☐ Not well
  ☐ Not at all
12. Where was this person born?
  ☐ The United States. (Fill in state)
  ☐ Outside of the United States. (Fill in name of country)
13. Is this person a citizen of the United States?
  ☐ Yes, born in the United States → SKIP to question 15a
  ☐ Yes, born in Puerto Rico, Guam, the U.S. Virgin Islands, or Northern Marianas
  ☐ Yes, born abroad of U.S. citizen parent or parents
  ☐ Yes, U.S. citizen by naturalization
14. When did this person come to live in the United States? (Fill in year)

The committee suggests using only question 12 (Where was this person born?) and question 14 (When did this person come to live in the United States?). For question 12, the standard response option is to list the state, including the District of Columbia. For those born in U.S. territories, such as Puerto Rico or Guam, individuals are instructed to respond "outside of the United States." For question 14, the response option is the year an individual came to live in the United States for the purpose of measuring period of entry, not the total years lived in the United States (Malone et al., 2003).

Common Metric

There is no commonly accepted metric for all of the concepts embedded here at this time.

Ratings of Measure by Committee

The two questions suggested by the committee are freely available and are highly feasible in a clinical setting. The brevity of the questions makes them easy to respond to and can be nonburdensome to the patient and on administrative personnel. Results from these questions can alert a health care provider to ask about the patient's preferred language and can potentially result in effective culturally and linguistically appropriate treatment. There may be sensitive issues in asking a patient's country of origin, which might inhibit accurate reporting and adversely affect patient–provider communication and trust. Because of these considerations, the committee rated the measure as follows in Table 4-3.

Limitations of Measure

As stated earlier, the clinical care team should be sensitive to individuals whose immigration status is questionable. Individuals whose immigration status is questionable may feel particularly vulnerable and may opt to not seek care or not follow up with their treatment if they feel threatened.

Specific Populations

A specific population for this domain measure is infants, children, and adolescent patients. For this population one can ask information on the parents' country of origin. Because younger-age populations' health outcomes are associated with their parents' social and economic backgrounds. Knowing parental country of origin/nativity may assist in improving the clinical outcome of these populations. Concerning immigration status, an infant, child, or adolescent of immigrant or refugee parents should be given special attention because questions are not asked of parents.

Education

Education is a well-established determinant of health at all stages of the life span. Educational attainment assesses the human capital dimension

TABLE 4-3 Ratings of the Measure on Country of Origin/U.S. Born Versus Non-U.S. Born

Domain Measure	Standard Measure and Freely Available (*** = most, * = least)	Usefulness (*** = most useful, * = least useful)	Feasible (*** = most feasible, * = least feasible)	Lack of Sensitive Information or Patient Discomfort (*** = least sensitive, * = most sensitive)	Committee Judgment of the Measure (*** = most, * = least)
U.S. Census: Country of Origin	***	**	***	*	**

of socioeconomic status (SES). It is strongly associated with other indices of SES, including occupational prestige and household income. Internationally, and to some extent among disadvantaged groups in the United States, increasing female education has been associated with considerable improvements in health and well-being.

Identification and Description of Measure

The committee reviewed two measures of education: one for highest degree earned, and another for highest year of schooling completed. Each has been shown to relate to a wide range of health outcomes. Although the two measures are highly related, some research has found a linear association of years of schooling and health while others have found discontinuities associated with earning degrees. The committee evaluated the education measures originally developed by the U.S. Census and expanded by the MacArthur Research Network on SES & Health (MacArthur Research Network on SES & Health, 2008).

For highest level of school that an individual completed, he or she is asked:

What is the highest level of school you have completed? Check one.

Elementary School	High School	College	Graduate/ Professional School
01___	09___	13___	17___
02___	10___	14___	18___
03___	11___	15___	19___
04___	12___	16___	20+___
05___			
06___			
07___			
08___			

For highest degree earned by the individual, he or she is asked:

What is the highest degree you earned? Check one.

- ☐ High school diploma
- ☐ GED
- ☐ Vocational certificate (post high school or GED)
- ☐ Association degree (junior college)
- ☐ Bachelor's degree
- ☐ Master's degree
- ☐ Doctorate

Common Metric

There is not a commonly accepted metric for these measures at this time.

Ratings of Measure by Committee

There is no fee for use of these measures, and their clarity and brevity make them highly feasible to be asked in a clinical setting or self-reported before the clinical encounter. These two measures will be useful for population health management. Education levels correlate with many health indicators, particularly as a health determinant and in their links to SES and health literacy, making it useful to capture them on a clinical level (Commission to Build a Healthier America, 2009; Woolf and Braveman, 2011; Woolf et al., 2007). The committee does not believe either question is sensitive. Because of these considerations, the committee rated the measure as follows in Table 4-4.

Limitations of Measure

A potential limitation of the two measures arises from the fact that neither captures the quality of the education received.

Specific Populations

Educational attainment can be problematic to measure for young adults whose education is not fixed. For those pursuing education later in life, a change to the frequency of capturing the information (originally a one-time capture) would be warranted. For most individuals, educational attainment plateaus by age 25. For children and adolescents, the most appropriate measure of education is their parent's educational attainment, rather than their grade level, because the intent of the concept is to characterize one aspect of an individual's SES. The agreement between adolescents and parents regarding parental educational attainment is moderately strong, with older adolescents reporting higher levels of agreement (Ensminger et al., 2000). For this reason, the committee recommends obtaining parental education directly from parents. However, adolescents 14 years and older may be able to provide reasonably valid assessments of their parents' educational attainment (Ensminger et al., 2000).

TABLE 4-4 Ratings of the Measure for Education

Domain Measure	Standard Measure and Freely Available (*** = standard, * = no standard)	Usefulness (*** = most useful, * = least useful)	Feasible (*** = most feasible, * = least feasible)	Lack of Sensitive Information or Patient Discomfort (*** = least sensitive, * = most sensitive)	Committee Judgment of the Measure (*** = highest rating, * = lowest rating)
Educational Attainment	***	***	***	***	***

Other Measures Reviewed

The committee believes that the measure of education should be as standardized as possible and, to this end, has recommended two common measures: one for highest grade level and one for highest degree obtained. There are several alternative questions that can be used to provide assessments of these metrics. The committee suggests that the MacArthur network questions be used because of the ease of administration and simplicity.

Employment

A large body of work has linked employment status, the type of occupation a person is engaged in, and specific job characteristics (including physical and psychosocial characteristics) to a broad range of health outcomes. There are many ways in which an individual's work exposures can be characterized. The simplest involves classifying persons based on their employment status. A second more complex option requires obtaining more information on the type of job so employed persons can be further classified in terms of the type of occupation or the occupational category they belong to, based on standard classifications (such as the U.S. Census). Yet a third option is to obtain measures of specific physical exposures (e.g., chemicals, noise, dust) or psychosocial exposures (e.g., demands, control, support) at work. All of these work dimensions have been shown to be strongly predictive of health and could have clinical and population utility.

Identification and Description of Measure

A person's employment status reflects their level of engagement with the workforce and has relevance to the clinician. It is also useful for population monitoring of employment trends. Although apparently straightforward, the questions used to characterize employment status in national surveys are often complex and involve a relatively large set of questions.

Standard measures used in national surveys such as the National Health and Nutrition Examination Survey (NHANES) are useful but were judged by the committee to be too long and complex to be included in the EHR. The committee evaluated the Multi-Ethnic Study of Atherosclerosis (MESA), a simple measure used in many population studies. These categories allow for a simple classification of the patient's current employment. The question and categories are as follows (MESA, 2005):

Choose one of the following which best describes your current occupation:

☐ Homemaker, not working outside the home

☐ Employed (or self-employed) full time
☐ Employed (or self-employed) part time
☐ Employed, but on leave for health reasons
☐ Employed, but temporarily away from my job (other than health reasons)
☐ Unemployed or laid off 6 months or less
☐ Unemployed or laid off more than 6 months
☐ Retired from my usual occupation and not working
☐ Retired from my usual occupation but working for pay
☐ Retired from my usual occupation but volunteering

Common Metric

There is not a commonly accepted metric for this measure at this time.

Ratings of Measure by Committee

The measure is freely available and the committee did not find the measures to be sensitive for patients. The committee found this question to be somewhat useful for systemic inclusion in EHRs. Due to its brevity, it is feasible to complete in the clinical setting. The question is straightforward and is not seen as being highly sensitive. Because of these considerations, the committee rated the measure as follows in Table 4-5.

Limitations of Measure

One of the limitations for the MESA measure is that it does not ask if the person is unemployed due to a disability. This is something that can be considered and addressed by possibly adding it as an option for selection. Additionally, the measure does not capture employment history or military service.

Specific Populations

For children and adolescents, parental employment status should be obtained.

Other Measures Reviewed

The committee gave serious consideration to the inclusion of other work and occupational measures, including characterization of type of occupation and other physical and psychosocial exposures at work for those employed. Although the committee recognized the value of identifying

TABLE 4-5 Ratings of the Measure for Employment

Domain Measure	Standard Measure and Freely Available (*** = standard, * = no standard)	Usefulness (*** = most useful, * = least useful)	Feasible (*** = most feasible, * = least feasible)	Lack of Sensitive Information or Patient Discomfort (*** = least sensitive, * = most sensitive)	Committee Judgment of the Measure (*** = highest rating, * = lowest rating)
MESA Employment Question	**	**	***	**	**

occupational categories, the process required to collect and then adequately code these data was judged too burdensome to be recommended for inclusion at this time. However, as discussed in Chapter 7, as the tools and instruments for characterizing occupation develop, this may become a high-priority measure for future inclusion in the EHR, given the high relevance of occupation and occupational exposure to the health of employed adults. For example, the National Institute for Occupational Safety and Health (NIOSH) is currently developing and standardizing specific measures that capture a patient's industry and occupation, including measures on work schedule, employment status, and external causes related to injury and poisoning (i.e., ICD-10 codes) (NIOSH, 2014). Although this information can be useful in identifying work exposures and conditions that are linked to health outcomes, the committee concluded that coding this information in an EHR was time intensive.

Financial Resource Strain: Food and Housing Insecurity

Financial resource strain is a composite of both subjective evaluation of economic difficulties and specific sources of strain, such as food insecurity or housing insecurity (Kahn and Pearlin, 2006). Food insecurity occurs when the availability of food is limited or uncertain (Scott and Wehler, 1998). It has been of interest not only as a reflection of overall economic strain but also because of its potential role in eating patterns that contribute to being overweight or obese (Dinour et al., 2007; Seligman et al., 2007). Individuals who experience periods of insufficient food availability may overconsume calories when food becomes available (Alaimo et al., 2001; Polivy, 1996; Taren et al., 1990; Townsend et al., 2001). In addition to obesity, food insecurity has been associated with physical health, mental health, and nutrition (Siefert et al., 2001; Szanton et al., 2010). Financial resource strain and insecurity (e.g., food, housing) are interconnected with one another along with other variables, often making it challenging to measure forms of insecurity independently from one another (Kahn and Pearlin, 2006; Siefert et al., 2001; Szanton et al., 2010). The phrases "food insufficiency" and "food insecurity" appear in the literature and are sometimes used interchangeably. Housing insecurity can range from an individual situation to community settings and is hard to measure because it is confounded with other variables (Kushel et al., 2006) (e.g., underemployment/unemployment, low wages, housing costs, and lack of access to the Supplemental Nutrition Assistance Program [SNAP]).

Identification and Description of Measures

The committee considered collection of patient income as a domain; however, the measures are complex, and short measures do not take into consideration issues such as wealth and assets, and that family income needs to be adjusted for the number of people dependent on the income. Additionally, individuals may not be comfortable disclosing this information, especially on an annual basis. Patient income overlaps with financial resource strain and geocoded median neighborhood income, which were ranked higher by the committee.

Overall financial resource strain For overall financial resource strain, the committee considered the work of Kahn and Pearlin (2006), a study of aging, stress, and the health consequences of repeated financial resource strain. They offer two approaches for the assessment of financial resource strain: one addressing current strain, and one addressing financial strain throughout the life span. The research demonstrated that both current financial strain and the number of periods of financial strain across the life span affect health outcomes. An alternative approach was employed in the Study of Women's Health Across the Nation (SWAN) and the Coronary Artery Risk Development in Young Adults (CARDIA) studies (see, for example, Hall et al. [2009] and Puterman et al. [2013]) that uses a single-item question. These studies indicate the single-item question to be a valid measure of general financial resource strain.

> How hard is it for you to pay for the very basics like food, housing, medical care, and heating? Would you say it is…
> Very hard
> Somewhat hard
> Not hard at all

Patients are asked to circle one of the options. The answer is then scored on a scale of 1 (very hard) to 3 (not at all), and unknown answers are scored as a negative number. Assessments were made at study entry and during the study at years 2, 5, 7, 10, 15, 20, and 25 (CARDIA, no date). Evidence from the CARDIA study demonstrates the value of measuring the difficulty of paying for basics over time (e.g., financial resource strain), because there appear to be cumulative effects (e.g., incident hypertension). The effects are independent of other SES measures (Matthews et al., 2002).

As stated earlier, financial resource strain has various composites, food insecurity and housing insecurity being two of those components. Food insufficiency is defined as food intake that is inadequate because of lack of resources (Briefel and Woteki, 1992). It is a valid measure for this domain, it has good evidence of validation (Lee and Frongillo, 2001), and it was seen to be actionable in a clinical setting.

Food insufficiency The food insufficiency measure has been used in NHANES III to measure an individual's food intake based on the reported adequacy of the family's food resources (Alaimo et al., 1998). The first question of the five-item set has been used to define restricted household food supplies or too little food intake among adults or children in the house hold. The question, when delivered orally, is (Siefert et al., 2001):

> Which of the following describes the amount of food your household has to eat:
> ☐ Enough to eat
> ☐ Sometimes not enough to eat
> ☐ Often not enough to eat

This single question has shown to hold external and face validity for the measurement of food insufficiency (Alaimo et al., 1998; Basiotis, 1992; Briefel and Woteki, 1992; Christofar and Basiotis, 1992).

Housing insecurity The financial resource strain subdomain that is the most difficult to measure is housing insecurity. From the review of the literature, there does not appear to be a measure that looks at housing insecurity by itself. Many of the studies look at housing instability, food insecurity, and economic instability combined (Kushel et al., 2006; Wallace et al., 2013). For example, in a study by Kushel et al. (2006), low-income individuals first self-reported if they had difficulty in paying rent, mortgage, or utility bills in the past year. Positive respondents were then asked "whether or not they had to move in with friends or family because they had no other choice."

Common Metric

There is no common metric for financial resource strain.

Ratings of Measures by Committee

The single question for *overall financial resource strain* is accepted, freely available, and shows a strong association with current health status. The single question used to measure *food insufficiency* is a standard measure that is also freely available and can be useful in identifying individuals and their household members who are having difficulty in accessing the appropriate amount of food on a regular basis. However, patients may feel uncomfortable answering that question. The committee noted that the single-question measure of financial resource strain includes food insecurity. There is no standard measure for *housing insecurity*. Because of these considerations, the committee rated the measures as follows in Table 4-6.

Limitations of Measures

As previously stated, financial resource strain and insecurity, such as food or housing, are interconnected and are therefore difficult to measure independent of one another.

Specific Populations

The food insufficiency questions should be asked of parents to characterize a child's family's food insecurity. Low-income individuals are a vulnerable population and should be asked these questions on a regular basis.

Other Measures Reviewed

In addition to the CARDIA and NHANES questions for evaluating financial resource strain, two other measures the committee reviewed were the BEST Index and the Elder Index developed by Wider Opportunities for Women (WOW, 2014). Both of these indices measure the income needed to achieve food, housing, and income security, as well as other expenses. However, these indices are population-based and are not made for use as an individual measure. Food insecurity can also be measured using a two-item instrument developed from affirmative responses given to the U.S. Department of Agriculture 18-item Household Food Security Survey (Hager et al., 2010; USDA, 2014). These two questions distinguish between hunger and food insecurity; however, this measure's limitation is that it has only been validated for families with children.

PSYCHOLOGICAL DOMAIN MEASURES

The candidate psychological domains covered below are described in the Ansari et al. (2003) model as psychosocial risk factors, whereas in the Kaplan et al. (2000) model the domains fall within the category of individual risk factors.

TABLE 4-6 Ratings for the Measures on Financial Resource Strain

Domain Measures	Standard Measure and Freely Available (*** = standard, * = no standard)	Usefulness (*** = most useful, * = least useful)	Feasible (*** = most feasible, * = least feasible)	Lack of Sensitive Information or Patient Discomfort (*** = least sensitive, * = most sensitive)	Committee Judgment of the Measure (*** = highest rating, * = lowest rating)
Overall Financial Resource Strain	***	***	***	**	***
Food Insufficiency	***	**	**	**	***
Housing Insecurity	*	**	*	**	*

Health Literacy

Health literacy, as stated in Chapter 3, is "the degree to which individuals have the capacity to obtain, process, and understand basic health-related decisions" (IOM, 2004, p. 20). Limited health literacy is common in the United States: 35 percent have basic or below basic health literacy; 53 percent have intermediate health literacy; and only 12 percent of adults are classified as proficient (Almader-Douglas, 2013; Kutner et al., 2006). Further, limited health literacy is associated with poor health outcomes (IOM, 2009), including higher hospitalization rates, greater use of emergency rooms as a source of regular care, and more adverse disease outcomes, as well as poor adherence to medications and a limited knowledge of health conditions (Baker et al., 1998; Berkman et al., 2004; Schillinger et al., 2002). Limited health literacy may place individuals at risk for poor health for several reasons, including creating difficulties in navigation through a convoluted health care system, in patient–provider interactions, and in self-care (HHS, 2008; Paasche-Orlow and Wolf, 2007). Health literacy is a complex domain with various dimensions (e.g., education, preferred language, culture, vision/hearing/cognitive ability). It is exacerbated by the complexity of health information and use of scientific medical terminology by the clinical health care team that may be unfamiliar to patients.

Identification and Description of Measure

The most widely used measures in the literature relating limited health literacy to adverse health outcomes are the Test of Functional Health Literacy in Adults (TOFHLA) and the Rapid Estimate of Adult Literacy in Medicine (REALM) (IOM, 2009). However, these scales are lengthy. The TOHFLA requires approximately 22 minutes to complete (NC Program on Health Literacy, 2014) and the REALM is a 66-item test (AHRQ, 2009). They also have complicated scoring procedures, are time-consuming to administer, and may require additional training of staff in order to administer them effectively.

A three-question measure has been derived to assess health literacy. These questions are as follows (Chew et al., 2004):

1. How often do you have someone (like a family member, friend, hospital/clinic worker or caregiver) help you read hospital materials?
   Always Often Sometimes Occasionally Never
2. How often do you have problems learning about your medical condition because of difficulty understanding written information?
   All of the time Most of the time Some of the time
   A little of the time None of the time

3. How confident are you filling out forms by yourself?
   All of the time   Most of the time   Some of the time
   A little of the time   None of the time

Responses are scored on a five-point Likert scale from zero to four. Chew et al. (2004) and Wallace et al. (2006) found that the three questions identified individuals with inadequate health literacy and compared favorably on receiver operator curve test characteristics with the Short TOFHLA area under the curve.

Common Metric

There is no common metric for this domain.

Rating of Measure by Committee

The three-question measure validated by Chew et al. (2004, 2008) may be useful for the clinical team in identifying those patients who have less than adequate or marginal health literacy. The brevity of the questions and the simplicity of the scoring make it feasible and nonburdensome for the patients to answer. Health literacy is a potentially sensitive area for patients, although framing this question as a query about the need for assistance might diminish potential stigmatization (compared with actual literacy tests).

However, although health literacy can be viewed as a characteristic of the individual, it operates in the context of the health care system—the clarity of communications from the health care system and individual providers' communication skills—as well as the patient's health literacy. As a result, adverse health effects of low health literacy can be reduced not just by identifying the needs and capacity of the individual patient but also by assuring the clarity of communication with all patients no matter what their literacy level.

All patients deserve clear communication, not just those deemed to have low health literacy levels. Thus, many have suggested that health care providers adopt a "universal precautions" approach to health literacy (Brown et al., 2004; Oates and Paasche-Orlow, 2009; Paasche-Orlow and Wolf, 2007; Rudd, 2010; Volandes and Paasche-Orlow, 2007). This approach offers strategies for clear communication using plain language for clear communication with all patients. An example is the use of *teach-back* techniques (IOM, 2004) that ask a patient to describe to a member of the clinical care team her or his understanding of their treatment plan. Such techniques can be useful in determining whether all patients comprehend and retain the information being provided to them. The Agency for Healthcare Research and Quality has developed a *Health Literacy Universal Precautions Toolkit* that details these approaches (AHRQ, 2014).

The committee concluded that health literacy can be best addressed through a universal precautions approach to ensure clear and effective communication with all patients, rather than measurement of the level of health literacy in individual patients. EHRs may have a role in assessing and documenting patient comprehension, although this potential is beyond the scope of this committee's review. Because of these considerations, the committee rated the measure as follows in Table 4-7.

Specific Populations

Although the REALM has been adapted for adolescents (Davis et al., 2006), brief measures of health literacy, such as the three questions that the committee evaluated, have not been adapted for pediatric populations. It may be more appropriate to assess parental health literacy for young children; parental levels of health literacy have been shown to relate to children's receipt of health services and their health outcomes (Sanders et al., 2009). As with adult literacy, a systems-focused approach may be more appropriate than an individual approach.

Other Measures Reviewed

The committee considered other scales, specifically, REALM-66, REALM-Short Form (SF), Short Assessment of Health Literacy for Spanish-speaking Adults (SAHLASA)-50, TOFHLA, Spanish (S)TOFHLA, and Newest Vital Signs (NVS). The majority of these scales have internal reliability, and their results correlated with at least one other scale. The REALM (and its abbreviated versions) and the TOFHLA (and its abbreviated versions) have been most studied for their correlation with health outcomes. However, these scales are not feasible to ask in a clinical setting.

Stress

Stress is a subjective state arising when an individual believes that he or she does not possess the resources to cope with a threatening situation, resulting in tension, restlessness, nervousness, or anxiousness. Acute and chronic stresses are types of stress experienced by individuals that have been linked to health outcomes. Acute stress is episodic and manifests during times of increased demands or pressures in response to anticipated threats (APA, 2014). Acute stress is short term and can have transient health

TABLE 4-7 Ratings of the Measure on Health Literacy

Domain Measure	Standard Measure and Freely Available (*** = standard, * = no standard)	Usefulness (*** = most useful, * = least useful)	Feasible (*** = most feasible, * = least feasible)	Lack of Sensitive Information or Patient Discomfort (*** = least sensitive, * = most sensitive)	Committee Judgment of the Measure (*** = highest rating, * = lowest rating)
Three-Question Measure from Chew et al. (2004)	***	*	***	**	*

effects, such as emotional distress and muscular problems. More serious health effects may emerge if such exposures are severe or persist over time. The chronic—sometimes termed *toxic*—stress of experiencing situations over an extended time that are perceived to be unmanageable and uncontrollable can create an "allostatic load" that increases the likelihood of serious health consequences (e.g., high blood pressure, cardiovascular disease, depression) (APA, 2014; Seeman et al., 2001). Adversities experienced in childhood may engender toxic stress that not only affects the child's health and well-being but may increase disease risk in adulthood as well (Felitti et al., 1998; Shonkoff et al., 2012).

Identification and Description of Measures

The committee considered two different approaches to stress measurement. Given the evidence of the importance of adverse early life exposures and links to adversity and stress, the committee examined the Adverse Childhood Experiences (ACE) tool. The ACE assesses chronic stress associated with experiencing multiple adversities in childhood (up to age 18). For example, individuals who had six or more ACEs were more likely to have a premature death than were those without ACEs, dying 20 years earlier on average (60.6 years, 95 percent confidence intervals [CIs] = 56.2, 65.4, versus 79.1 years, 95 percent CI = 78.4, 79.9, respectively) (Brown et al., 2009). Additionally, in another study, results indicate an increased graded-dose response between ACE scores and comorbid outcomes of substance abuse, impaired memory, sexuality (early intercourse, promiscuity, or sexual dissatisfaction), aggression, and somatic disturbances (Anda et al., 2005). The original ACE index developed by Felitti et al. (1998) asked adults 17 questions regarding exposures such as abuse and neglect, parental marital status, mental illness, and incarceration. ACE researchers and the CDC developed a standardized ACE module for use in the Behavioral Risk Factor Surveillance System (BRFSS). The following are the adapted BRFSS ACE's questions (Institute for Safe Families, 2013):

> While you were growing up, that is during your first 18 years of life, how often, if ever, did a parent, step-parent, or another adult living in your home…
>
> 1. How often did a parent or adult in your home ever swear at you, insult you, or put you down?
>   More than once Once Never
> 2. How often did your parents or an adult in your home ever hit, beat, kick or physically hurt you in any way? Do not include spanking.
>   More than once Once Never

3. How often did anyone at least 5 years older than you or an adult ever touch you sexually?
   More than once Once Never
4. How often did anyone at least 5 years older than you or an adult ever try to make you touch them sexually?
   More than once Once Never
5. How often did anyone at least 5 years older than you or an adult ever force you to have sex?
   More than once Once Never
6. How often did your parents or adults in your home ever slap, hit, kick, punch, or beat each other up?
   More than once Once Never
7. Did you live with anyone who was a problem drinker or alcoholic?
8. Did you live with anyone who used illegal street drugs or who abused prescription medications?
9. Did you live with anyone who was depressed, mentally ill, or suicidal?
10. Were your parents separated or divorced?
11. Did you live with anyone who served time or was sentenced to serve time in prison, jail, or other correctional facility?

Scores on the ACE obtained in adulthood are associated with various poor health outcomes (e.g., impaired memory, substance abuse, somatic disturbances), as stated in the above text.

To obtain a measure of current stress, the committee evaluated a single question developed by Elo et al. (2003). This question is associated with indicators of health and psychosocial work characteristics, and it can be used for monitoring stress in work-life contexts. The single-item question is:

> Stress means a situation in which a person feels tense, restless, nervous, or anxious, or is unable to sleep at night because his/her mind is troubled all the time. Do you feel this kind of stress these days?
>
> Not at all A little bit Somewhat Quite a bit Very much

The response is recorded on a five-point Likert scale ranging from 1—indicating not at all, 2—a little bit, 3—somewhat, 4—quite a bit, to 5—indicating very much. This single question shows content validity as well as concurrent criterion validity. The single question converged with items on psychological symptoms and sleep disturbances and with validated measures of well-being (Elo et al., 2003).

Common Metric

No common metric is available for either chronic or acute stress.

Ratings of Measures by Committee

The ACE measure is increasingly used in research, and evidence is accumulating that adverse childhood experiences set a trajectory for poor health into adulthood. It is of moderate length and asks very sensitive information about the patient's background exposures. Its usefulness is primarily to understand the patient's background and factors that may help the clinician understand the patient's current health and health behaviors. It is deemed of modest priority for inclusion in the EHR. ACE questions can be asked only once in an adult's life span.

The single-question measure by Elo et al. (2003) is freely available and has been assessed by the committee to be highly feasible for inclusion in the EHR and it is moderately sensitive in nature, potentially causing patient discomfort. The measure can also be linked to the PROMIS Emotional Distress (Depression and Anxiety) Short Form scales, which also are reliable and are valid ways to assess stress.

Because of these considerations, the committee rated the measures as follows in Table 4-8.

Limitations of Measures

ACE is a retrospective assessment of exposures to profound family stressors. Validation of the scale derives from studies of associated risk for chronic disease and early mortality. It is not clear what action can be taken should patients have high scores, independent of standard treatment for the potential health consequences of these family stressors that the patients experience.

The single-question (Elo et al., 2003) stress measure is scored on a five-point Likert scale that has been primarily tested in Scandinavian populations. There is no clinical cutoff for determining when interventions, such as referral to stress management, are warranted.

Specific Populations

The adverse childhood experiences measure can be used for adult populations; comparable versions for pediatric populations have yet to be validated for either the ACEs or the Elo et al. (2003) stress measure.

TABLE 4-8 Ratings of the Measures for Stress

Domain Measures	Standard Measure and Freely Available (*** = standard, * = no standard)	Usefulness (*** = most useful, * = least useful)	Feasible (*** = most feasible, * = least feasible)	Lack of Sensitive Information or Patient Discomfort (*** = least sensitive, * = most sensitive)	Committee Judgment of the Measure (*** = highest rating, * = lowest rating)
Adverse Childhood Experiences (ACE)	***	*	**	*	*
Single Question from Elo et al. (2003)	***	***	***	**	***

Other Measures Reviewed

The committee reviewed the British-developed "distress thermometer," which is a visual analog scale to rate emotional distress ranging from 0 (no distress) to 10 (extreme distress) (Roth et al., 1998). However, this tool's limitation is that it also measures depression and anxiety and does not specifically screen for stress (Mitchell, 2007), making a diagnosis more challenging. In addition, the committee considered the National Institutes of Health (NIH) Toolbox Perceived Stress Survey, but due to its length (10 questions), it was not seen as feasible for the clinical encounter (Slotkin et al., 2012).

Depression

There are many well-validated measures of depressive symptoms. For the EHR, the committee reviewed several screening and monitoring measures. The committee deliberated on one measure that screens the patient for depression symptoms and, if positive, would lead to further referrals for clinical evaluation, and on a second measure for monitoring symptom changes over time.

Identification and Description of Measures

For an initial patient screen for depression the committee considered the Patient Health Questionnaire (PHQ) for depression, which is a commonly used screener in diverse clinical settings. The PHQ-9 contains nine symptom items rated on a four-point scale that measures the frequency of experiencing depressive symptoms during the past 2 weeks, from "not at all" (0 points) to "nearly every day" (3 points). The PHQ-9 is a reliable instrument, with Cronbach's alpha coefficients ranging from 0.86 to 0.89, and test-retest reliability across 48 hours with an alpha coefficient of 0.84 (Kroenke et al., 2001). This scale and the shortened version described below are associated with other measures of negative emotions, quality of life, number of office visits, and disability measures, all of which support the validity of the scale.

Two questions taken from the PHQ-9 have been validated for use as a screen for depression. The briefer PHQ-2, with a cutoff of greater than or equal to three, has a sensitivity of 83 percent and a specificity of 92 percent for major depression, relative to independent structured interviews by mental health professionals (Kroenke et al., 2003). The PHQ-2 question is the following (Kroenke et al., 2003) and is scored from 0 (not at all) to 3 (nearly every day):

Over the past 2 weeks, how often have you been bothered by any of the following problems:

1. Little interest or pleasure in doing things
   Not at all   Several days   More than half the days   Nearly every day
2. Feeling down, depressed or hopeless
   Not at all   Several days   More than half the days   Nearly every day

For monitoring patients with a positive initial depression screen, the committee considered the Patient Reported Outcomes Measurement Information System (PROMIS) Depression Scale, which measures mood in the last week. It is available in short forms (eight-item, six-item, and four-item) as well as in a computerized adaptive test (CAT) version. The PROMIS-8b short form has also been shown to assess depressive symptoms as well as other longer scales (e.g., PHQ-9, Center for Epidemiology Studies Depression Scale [CESD]-10) (Kim et al., 2012), having an item correlation with CESD-10 of 0.83 to 0.88 (Amtmann et al., 2014; Choi et al., 2014). PROMIS depression instruments are available in adult and pediatric versions and are related to other measures of negative emotion, especially anxiety. The scale is a valid instrument for monitoring patients who initially screen positive for depressive symptoms or are depressed. The PROMIS-8b for depression asks how often in the past 7 days—from 1 (never) to 5 (always)—a person had each of eight feelings:

In the past 7 days:
1. I felt worthless
2. I felt that I had nothing to look forward to
3. I felt helpless
4. I felt sad
5. I felt like a failure
6. I felt depressed
7. I felt unhappy
8. I felt hopeless

Common Metric

Both the PHQ-2 and the PROMIS-8b short form can be scored on the PROMIS Depression T-scale, which serves as the common metric for depressive symptoms. The PROMIS Depression T-score has a mean of 50 (centered on the U.S. population average) and a standard deviation of 10 (PROMIS, 2014b). Developers of PROMIS are conducting research that allows clinicians and investigators to translate the scores from other depression measures, specifically the Beck Depression Inventory, and the PHQ-9, into PROMIS T-scores.

The PHQ-9 is based on the DSM-IV criteria for depression and, as such, maps onto the diagnostic criteria for depression. Thus, the clinical cutoff of yes or no risk for depression is a common diagnostic metric that can be approximated by the PHQ-2.

Ratings of Measure by Committee

The PHQ-2 will be useful for health care providers to identify those patients at risk for depression. Depression is comorbid with many chronic illnesses and, when treated, may lead to improvement in health more generally. The brevity of the scale and its simplicity of scoring make it highly feasible. It is a somewhat sensitive measure because of the stigma associated with depression, and it should be followed by fuller evaluation and support services. The committee believes the PHQ-2 will be useful in EHR because of the impact of depression on many illnesses and disabilities and because effective treatments are available. It is likely to be especially useful to include during known periods in the life span of increased vulnerability to depression, such as postpartum women, perimenopausal women, and the elderly.

The PROMIS-8b short form is helpful in monitoring change in symptoms over time. Like the PHQ-2, the information is somewhat sensitive because of stigma associated with depression. An advantage of PROMIS is that studies have been conducted to allow cross-scale comparisons.

Because of these considerations, the committee rated the measures as follows in Table 4-9.

Limitations of Measure

The primary limitation of the PHQ-2 is a concern about the management challenges that the health system may face in following up on what may be a substantial number of patients who have a positive depression screen. However, given the impact of depression on many aspects of life, including its contribution to other disease states, this is a legitimate and an important demand on the health care system.

Specific Populations

There are life periods when special care is required for diagnosis and treatment for pediatric samples, for women, and for the elderly. One advan-

TABLE 4-9 Ratings of the Measures for Depression

Domain Measures	Standard Measure and Freely Available (*** = standard, * = no standard)	Usefulness (*** = most useful, * = least useful)	Feasible (*** = most feasible, * = least feasible)	Lack of Sensitive Information or Patient Discomfort (*** = least sensitive, * = most sensitive)	Committee Judgment of the Measure (*** = highest rating, * = lowest rating)
PHQ-2	***	***	***	**	***
PROMIS-8b	***	*	**	**	*

tage of the PROMIS Depression Scale is that there is a pediatric version that is conceptually harmonized with the adult version. For detection of postpartum depression and depression among the elderly, either the PHQ-2 or the PROMIS-8b depression measures would be a reasonable choice.

Depending on the level of disability, individuals with intellectual disability may present with atypical symptoms of mood disorders (e.g., depression, anxiety), and they may have limited speech capabilities (Hurley, 2006). Individuals with mild levels of intellectual disabilities can use self-reported measures (e.g., PHQ-9, PROMIS-8b) for diagnosing depressive symptoms or depression. However, more research is needed for developing adequate measures for individuals with severe intellectual disabilities (Hermans and Evenhuis, 2010).

Other Measures Reviewed

The committee considered other widely used and validated scales, specifically, the CES-D scale and the WHO-K6 or K10 scales. The latter scales cover serious mental illness more broadly, whereas the CES-D is designed for use in epidemiological studies. The CES-D has clinical cutoffs and can be used to monitor changes in depressive symptoms during treatment. However, it contains 20 items, which makes it less feasible within the constraints of the EHR.

Anxiety

Like depression scales, anxiety measures are plentiful. For the EHR, the committee deliberated on several measures, including the Generalized Anxiety Disorder Scale (GAD-7) and the PROMIS Anxiety Scales.

Identification and Description of Measures

The GAD-7 contains seven items based on clinical diagnostic criteria for generalized anxiety disorder. The questions concern anxious feelings, worrying, and trouble relaxing in the past 2 weeks. It has excellent reliability, with Cronbach's alpha coefficient equal to 0.92, a test-retest reliability of 0.83, and a sensitivity and specificity of 89 percent and 82 percent, respectively (Spitzer et al., 2006). It is correlated with other anxiety scales and diagnosis of generalized anxiety disorder. It is related to measures of quality of life, disability symptoms, and illness visits. The seven questions are as follows and each of the items is scored from 0 (not at all) to 3 (nearly every day) (Spitzer et al., 2006):

Over the past 2 weeks, how often have you been bothered by the following problems?

1. Feeling nervous, anxious, or on edge
2. Not being able to stop or control worrying
3. Worrying too much about different things
4. Having trouble relaxing
5. Being so restless that it is hard to sit still
6. Becoming easily annoyed or irritable
7. Feeling afraid as if something awful might happen

Like the PROMIS depression instruments, the PROMIS anxiety instruments are available in short versions (eight-item, seven-item, six-item, and four-item). All the short PROMIS anxiety instruments are similar in reliability and precision for screening anxiety symptoms. The PROMIS anxiety instruments are available in adult, pediatric, and parent proxy versions (PROMIS, 2014a). This measure asks about anxiety levels in the past week for symptoms, including fear, anxiousness, misery, and hyper-arousal symptoms. The PROMIS-7a has an internal consistency reliability score of 0.90 (PROMIS, 2014a) and is highly correlated with the Mood and Anxiety Symptoms Questionnaire (MASQ) (Pilkonis et al., 2011). This instrument asks the following questions about how often in the past week the person experienced each of the following feelings, from never (0) to always (5):

In the past 7 days…

1. I felt fearful
2. I found it hard to focus on anything other than my anxiety
3. My worries overwhelmed me
4. I felt uneasy
5. I felt nervous
6. I felt like I needed help for my anxiety
7. I felt anxious

Common Metric

Like other PROMIS scales, PROMIS anxiety scores are T-scores with a standard deviation of 10 developed based on large community and clinical samples. The PROMIS Anxiety T-score has a mean of 50 (centered on the U.S. population average) and a standard deviation of 10 (PROMIS, 2014a). Ongoing investigations are providing ways to link measures provided by other anxiety scales (e.g., MASQ, GAD-7, and the Positive and Negative Affect Scale [PANAS]) to the PROMIS norms (Schalet et al., 2013).

Ratings of Measures by Committee

Because anxiety often accompanies depressive symptoms, the committee downgraded the usefulness of a separate measure of anxiety within the EHR. Like measures of depression, it is feasible to collect, especially if the PROMIS CAT measure is used. Because of these considerations, the committee rated the measures as follows in Table 4-10.

Limitations of Measure

The primary limitation concerns whether the health system can manage adequate follow-up of patients likely to report high levels of anxiety symptoms.

Specific Populations

As stated earlier, the PROMIS anxiety instruments include both adult and pediatric versions. The pediatric version is self-reported by children as young as 8 years of age, and using parent-proxy, it is reported for children of 5 to 7 years of age. There is no PROMIS measure for children younger than 5 years of age.

Other Measures Reviewed

The GAD-2 short form instrument, derived from GAD-7, had a sensitivity of 86 percent for generalized anxiety disorder, 76 percent for panic disorder, 70 percent for social anxiety disorder, along with reliable specificity (83 percent to 81 percent) for these disorders (Kroenke et al., 2007). The GAD-2 questions can be used in combination with the PHQ-2 to screen for anxiety and depression.

Conscientiousness

Conscientiousness is a complex trait composed of propensity to be self-controlled, to be task and goal directed, to delay gratification, and to follow norms and rules. It is challenging to measure the full array of factors that constitute conscientiousness.

Identification and Description of Measure

Conscientiousness is measured typically as part of personality scales that assess five major personality characteristics, sometimes called the "Big

TABLE 4-10 Ratings of the Measures for Anxiety

Domain Measure	Standard Measure and Freely Available (*** = standard, * = no standard)	Usefulness (*** = most useful, * = least useful)	Feasible (*** = most feasible, * = least feasible)	Lack of Sensitive Information or Patient Discomfort (*** = least sensitive, * = most sensitive)	Committee Judgment of the Measure (*** = highest rating, * = lowest rating)
GAD-7	***	**	***	**	**
PROMIS-7a	***	**	***	**	**

Five." The scales measuring the Big Five have several variants, with up to 105 items. There have been efforts to develop briefer versions of the Big Five personality characteristics (see Bogg and Roberts [2004] for an overview). A commonly used one for research purposes is the Big Five Inventory (BFI), which has nine items measuring conscientiousness; these items are rated on a five-point scale, ranging from 1 (disagree strongly) to 5 (agree strongly) and summed after appropriate reverse scoring of specific items (Rammstedt and John, 2007). Even shorter versions are available and validated. However, in general, they are not as reliable and valid as the longer scales. One of the shorter scales is the BFI-10 items, which contains two items that comprise the conscientious subscale (Rammstedt and John, 2007):

I see myself as someone who:
  ☐ Tends to be lazy
  ☐ Does a thorough job

Common Metric

There is no current common metric for conscientiousness.

Ratings of Measure by Committee

Use of the measure of conscientiousness, based on the Neuroticism-Extraversion-Openness (NEO) Personality Inventory Revised, was determined to have some limitations because it is copyrighted and lengthy. The BFI (44 questions, with 9 for conscientiousness) is available for researchers, and the owner of the copyright may grant permission to use these measures to EHR vendors in the interest of patient care and research.[2]

Although the evidence is strong that conscientiousness is consistently related to longevity and positive health behaviors, including adherence, the committee deemed it low priority for inclusion in EHRs because of a lack of evidence on how to intervene on patient conscientiousness. It is theoretically possible to develop programs to aid patients in developing organizational skills, which is one part of conscientiousness, but that is only one aspect, and no evidence exists on the effectiveness of such training. Because of these considerations, the committee rated the measure as follows in Table 4-11.

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[2] Personal communication, Oliver John, University of California, Berkeley, August 5, 2014.

TABLE 4-11 Ratings of the Measure for Conscientiousness

Domain Measure	Standard Measure and Freely Available (*** = standard, * = no standard)	Usefulness (*** = most useful, * = least useful)	Feasible (*** = most feasible, * = least feasible)	Lack of Sensitive Information or Patient Discomfort (*** = least sensitive, * = most sensitive)	Committee Judgment of the Measure (*** = highest rating, * = lowest rating)
Big Five Inventory-2 of 10 Questions	**	**	**	***	*

Limitations of Measure

A potential limitation of using the BFI or its subscales is that the items are not unambiguously freely available to all users (John, 2007–2009). Permission is routinely granted for free use for research and noncommercial use. The copyright holder for the BFI has indicated his willingness to give permission for use in EHRs because these will be used to advance treatment and research.

Specific Populations

A pediatric version of the BFI, long form, that is completed by parents has been developed (John, 2007–2009).

Other Measures Reviewed

There is a two-item conscientiousness scale from the 10-item Personality Inventory. Each item is rated on a 7-point scale ranging from 1 (disagree strongly) to 7 (agree strongly) with the stem, "I see myself as" followed by the two items: (a) dependable, self-disciplined, and (b) disorganized, careless. The latter is reverse scored. This scale is freely available, feasible, low burden, and not sensitive. Note that this is a separate measure than that noted above. However, there is little research using the shorter measures in relation to health and there is only a moderate correlation between the two-item measures and longer measures (John, 2007–2009).

Patient Engagement/Activation

Patient engagement/activation encompasses an individual's attitudes, skills, and knowledge that enable him or her to engage in health care in an active, full, and meaningful manner.

Identification and Description of Measure

Currently, only one measure has been validated for the assessment of this psychological asset—the Patient Activation Measure (PAM). A PAM score has the ability to predict health care outcomes (e.g., medication adherence, hospitalizations) (Inigma, 2014). The PAM instrument began as a 22-item questionnaire that measured unidimensional, self-management variables using a Guttman-like measure (Hibbard et al., 2004), and it was then shortened to a 13-item measure. The shorter version has a small loss in precision within some subgroups. Because the PAM instrument is not freely available, the items are not listed here.

Common Metric

There is no common metric for patient engagement/activation at this time.

Ratings of Measure by Committee

The PAM is not freely available to health care providers or health systems because of copyright protections. Recent research reports an association between patient engagement/activation and health outcomes (Brenk-Franz et al., 2013; Hibbard and Greene, 2013), but perhaps because of limitations on its use, there is limited research on which to base estimates of usefulness. Because of these considerations, the committee rated the measure as follows in Table 4-12.

Limitations of Measure

The PAM is not freely available to health care providers due to copyright protections.

Other Measures Reviewed

Measures related to the PAM have been developed for patients with specific diseases, but no validated measures of patient activation that would be appropriate for the diverse types of patients served by EHRs have been published.

Optimism

Identification and Description of Measure

The prevailing measure of optimism is the Life Orientation Test-Revised (LOT-R), which contains six questions regarding expectations for positive and negative outcomes. Each question is rated on a four-point scale. Test-retest reliability is 0.79 across 28 months, and Cronbach's alpha coefficient is 0.78 for the six questions, demonstrating acceptable internal validity (Scheier et al., 1994). It correlates with other positive assets, such as self-esteem and self-mastery, and negatively with negative attributes, such as anxiety and neuroticism. The LOT-R items are the following (Scheier et al., 1994)[3]:

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[3] The original LOT-R has four filler questions; they are omitted here.

TABLE 4-12 Ratings of the Measure for Patient Engagement/Activation

Domain Measure	Standard Measure and Freely Available (*** = standard, * = no standard)	Usefulness (*** = most useful, * = least useful)	Feasible (*** = most feasible, * = least feasible)	Lack of Sensitive Information or Patient Discomfort (*** = least sensitive, * = most sensitive)	Committee Judgment of the Measure (*** = most, * = least)
PAM	*	*	**	***	*

> Be as honest as you can throughout, and try not to let your responses to one question influence your responses to other questions. There are no right or wrong answers.
>
> 1. In uncertain times, I usually expect the best.
> 2. If something can go wrong for me, it will.
> 3. I'm always optimistic about my future.
> 4. I hardly ever expect things to go my way.
> 5. I rarely count on good things happening to me.
> 6. Overall, I expect more good things to happen to me than bad.

The questions are scored on a five-point Likert scale, from 0 (strongly disagree) to 4 (strongly agree). Given that most samples score on average to be somewhat optimistic, it may be useful to examine the three positive expectation and three negative expectation subscales separately.

Common Metric

There is not a commonly accepted metric for optimism at this time.

Ratings of Measure by Committee

This scale is rated as low in patient burden, high in ease of administration, and unlikely to cause stigmatization. The measure was judged to be moderately useful in the context of delivery of clinical care and identifying individuals who might require additional supports. This domain was the most highly rated of the positive assets because of the strength and consistency of association of the evidence linking optimism with adherence to behavior change, positive health behaviors, and mortality. Reservations about the measure's actionability led to the lower overall ratings on the measure's usefulness. Because of these considerations, the committee rated the measure as follows in Table 4-13.

Limitations of Measure

The LOT-R is a research instrument and is not intended for clinical applications. There is no clinical cutoff for optimism (University of Miami Department of Psychology, 2007).

TABLE 4-13 Ratings of the Measure for Optimism

Domain Measure	Standard Measure and Freely Available (*** = standard, * = no standard)	Usefulness (*** = most useful, * = least useful)	Feasible (*** = most feasible, * = least feasible)	Lack of Sensitive Information or Patient Discomfort (*** = least sensitive, * = most sensitive)	Committee Judgment of the Measure (*** = highest rating, * = lowest rating)
Life Orientation Test-Revised	***	**	***	***	**

Specific Populations

The LOT has been adapted for youth self-report (YLOT, between third and sixth grade) (Ey et al., 2005) and for parent-proxy report for younger children (PLOT) (Lemola et al., 2010).

Self-Efficacy

Self-efficacy is defined as the confidence to carry out or produce a specific behavior or make a change in a specific behavior (e.g., exercise three times per week for 60 minutes). It is defined within the context of social learning theory, which has proved useful to guide interventions requiring behavior change. Another perspective is generalized self-efficacy, which is the confidence that one can deal with demands and stressful circumstances more broadly.

Identification and Description of Measures

One way of measuring self-efficacy for specific behaviors is by using Bandura's *Guide for Constructing Self-Efficacy Scales* (Bandura, 2006). Construction of these scales requires analysis of the specific domain, including knowledge of the behavior involved and assessment of aspects of behavior control, and identifications of challenges that may derail a person's success. According to Bandura (2006, p. 310), "Behavior is better predicted by people's beliefs in their capabilities to do whatever is needed to succeed." Efficacy scales are unipolar, ranging from minimum strength (0) to maximum strength (100), with intervals of 10 to form the ratio scales. The Alcohol Abstinence Self-Efficacy Scale (DiClemente et al., 1994), for example, is a 20-item scale developed to assess a person's self-efficacy regarding alcohol abstinence. Specific scales have been developed and validated for other behaviors (e.g., smoking cessation [Etter et al., 2000], nutrition-related or dietary patterns [Anderson et al., 2000], physical exercise [Schwarzer and Renner, 2000]).

Generalized self-efficacy can be assessed by using NIH's self-efficacy measure, the NIH Toolbox Self-Efficacy Survey. This survey measures an individual's generalized confidence to handle stressful circumstances. It contains 10 questions rated according to how true the statement is of the person on a five-point scale. It has versions for adult and pediatric samples. The 10-item questions are as follows (NIH, 2006–2012):

Please read the sentence and describe how true it is of you in general.

1. I can manage to solve difficult problems if I try hard enough.
2. If someone opposes me, I can find the means and ways to get what I want.
3. It is easy for me to stick to my aims and accomplish my goals.
4. I am confident that I could deal efficiently with unexpected events.
5. Thanks to my talents and skills, I know how to handle unexpected situations.
6. I can solve most problems if I try hard enough.
7. I stay calm when facing difficulties because I can handle them.
8. When I have a problem, I can find several ways to solve it.
9. If I am in trouble, I can think of a solution.
10. I can handle whatever comes my way.

The questions are scored on a five-point scale ranging from 1 (never) to 5 (very often).

Common Metric

There is no common metric for self-efficacy at this time. The NIH Toolbox measure of generalized self-efficacy has normative data that could be used to develop a common metric for self-efficacy among adults.

Ratings of Measures by Committee

There is no standard measure of self-efficacy for specific behaviors. Although any measure that may be constructed is typically short, easy to ascertain, and unlikely to be sensitive, a dictionary of behaviors would need to be developed to be useful for patient care. The NIH Toolbox is widely used in research and clinical settings and is standardized. It can be easily collected although it is somewhat long. Its usefulness is limited, however, because it is not specific to the situations involved in health care. Because of these considerations, the committee rated the measures as follows in Table 4-14.

Limitations of Measure

The NIH Toolbox measure was recently developed. Further research is needed to better understand its performance and utility in clinical settings.

TABLE 4-14 Ratings of the Measures for Self Efficacy

Domain Measures	Standard Measure and Freely Available (*** = standard, * = no standard)	Usefulness (*** = most useful, * = least useful)	Feasible (*** = most feasible, * = least feasible)	Lack of Sensitive Information or Patient Discomfort (*** = least sensitive, * = most sensitive)	Committee Judgment of the Measure (*** = highest rating, * = lowest rating)
Self-Efficacy Scales for Specific Behaviors	*	*	*	***	*
NIH Toolbox of Generalized Self-Efficacy	***	*	***	***	*

Specific Populations

There are no pediatric measures of self-efficacy at this time.

BEHAVIORAL DOMAIN MEASURES

The candidate behavioral domains include dietary patterns, physical activity, tobacco use and exposure, and alcohol use.

Dietary Patterns

Dietary patterns (summary measures of food consumption) are often examined in the research setting to capture their associations with health, and they are increasingly used in the clinical setting to guide lifestyle counseling. Nutrition is important to health but complex to measure because it encompasses caloric intake, the macronutrients found in food (e.g., fats, proteins, carbohydrates), the micronutrients (e.g., vitamins, minerals), and non-nutritional ingredients (e.g., sugar).

After examining possible measures of nutrition, the committee focused on the subdomain of fruit and vegetable intake and frequency because of the availability of appropriate measures for this aspect of nutrition. Although caloric intake, sugar intake, and energy expenditure are also important components of nutrition, short validated measures assessing them do not exist at this time.

Identification and Description of Measure

Consumption of fruits and vegetables is highly correlated with health outcomes. For the EHR, the committee evaluated the two-question measure developed and used in a British study by Wardle et al. (2000) and validated by Cappuccio et al. (2003) for fruit and vegetable intake with biomarkers. These same measures have been used and validated in various food assessment studies across various British populations. (See, for example, Baker and Wardle, 2003; Little et al., 1999; and Wardle et al., 2005.) These two questions are:

1. How many pieces of fruit, of any sort, do you eat on a typical day?
2. How many portions of vegetables, excluding potatoes, do you eat on a typical day?

These questions have high specificity, identifying more than 80 percent of individuals with biomarker profiles indicative of low fruit and vegetable intake (i.e., consuming less than five portions of fruits and vegetables per day), which is the case for the majority of the U.S. population. These studies used the British Dietetic Association's guidelines (BDA, 2014) to define what it meant by *portion*, which is comparable to the U.S. Department of Agriculture's Recommended Guidelines for Americans (USDA, 2013). It is important to note, however, that portion size corresponds to the amount of a single food item an individual eats in one sitting, which is different from serving size, a standardized unit of a measured single food (CDC, 2006a).

Common Metric

There is no common metric for dietary patterns at this time.

Ratings of Measure by Committee

The two-question measure used by Cappuccio et al. (2003) was assessed by the committee to be highly feasible and with few concerns about the measure containing sensitive information and thus causing patient discomfort.

Additionally, it was thought to represent a useful screening tool as a marker of a healthy or unhealthy diet. However, while the committee considers collection of data on nutrition to be a priority, this measure to capture data on dietary patterns is not as robust as other measures the committee reviewed; it was also viewed to be only moderately useful due to limitations of the measure (see below) and because the clinical intervention is unclear.

Because of these considerations, the committee rated the measure as follows in Table 4-15.

Limitations of Measure

This measure captures only one aspect of nutrition. Other limitations of the measure include a lack of clarity regarding the term *portion* and insufficient information on the measure's stability and the needed frequency of screening.

Weight is routinely collected by the clinical care team, and the committee considered that addressing issues related to a patient being overweight or obese would trigger behavioral counseling interventions related to healthy diet and weight even without a measure of dietary patterns. Typical health risk assessments most likely include fruit and vegetable consumption as well as other risks such as those associated with processed meats.

TABLE 4-15 Ratings of the Measure for Dietary Patterns

Domain Measure	Standard Measure and Freely Available (*** = standard, * = no standard)	Usefulness (*** = most useful, * = least useful)	Feasible (*** = most feasible, * = least feasible)	Lack of Sensitive Information or Patient Discomfort (*** = least sensitive, * = most sensitive)	Committee Judgment of the Measure (*** = highest rating, * = lowest rating)
Fruit and Vegetable Consumption	***	**	***	***	**

Specific Populations

Typical and recommended dietary patterns of children vary from adults, as do rewards for certain dietary patterns. For children and adolescents, consideration should be given to adding questions on intake of sweetened beverages, such as soda and fruit drinks. However, it is noted that adults also suffer from obesity linked with consumption of sweetened beverages. Further, because sugar is included in so many foods, it was unclear to the committee if measuring only sugar-sweetened beverages would be sufficient. This is an emerging area of science.

Other Measures Reviewed

Measures of specific dietary patterns (e.g., the eight-item Starting the Conversation screen, the Dietary Approaches to Stop Hypertension diet, and the Mediterranean diet) were reviewed, but they are potentially more time-consuming for patients to respond to; some measures are not clinically freely available; and if high-risk patients are identified, behavioral interventions need to be easily referable from the clinical setting. The Block Food Questionnaire available from NutritionQuest is a strong measure of sugar consumption, but it has more than 125 questions and is a proprietary tool.

Physical Activity

Physical activity refers to skeletal muscle movement resulting in energy expenditure that exceeds resting levels (Caspersen et al., 1985). Physical activity can be done purposefully, or as part of daily life, work, school, or fun; it can be a modifiable determinant of health.

Identification and Description of Measure

Physical activity can be assessed using direct ascertainment provided by devices that detect movement or via self-reported questionnaires. Methods of direct ascertainment include devices such as accelerometers, pedometers, and heart rate monitors. These devices must be worn by the patient as a wristwatch or a waistband or attached to clothing. They assess the amount an individual moves (i.e., motion) or the impact of movement on physiology, such as the change in heart rate associated with motion. Physical activity questionnaires ask respondents to report recent participation in movement behaviors, typically over a short interval or as a diary of types and duration of specific types of physical activities. Self-report assessment methods may require retrospective recall or involve prospective data gathering of data for 1 to 7 days.

In both cases, a measure of metabolic equivalent of task minutes (MET-minutes) can be obtained. Based on the stipulation that health benefits are achieved with 500 to 1,000 MET-minutes per week, the Physical Activity Guidelines Advisory Committee, formed by the Office of Disease Prevention and Health Promotion within the U.S. Department of Health and Human Services (HHS), recommended 150–300 minutes per week of moderate-intensity or 75 minutes per week of vigorous-intensity activity to provide substantial health benefit (Physical Activity Guidelines Advisory Committee, 2008).

The committee evaluated the measurement properties of two specific measures: the Exercise Vital Sign and accelerometry. Both can be used to produce MET-minutes per week. The Exercise Vital Sign is a modified version of the physical activity questions in the BRFFS. It is a two-question measure that does not have licensing fees. Feasibility studies have shown that it can be readily integrated into the EHR (Coleman, 2012). The measure assesses minutes per week spent in moderate to vigorous exercise. The questions are:

1. On average, how many days per week do you engage in moderate to strenuous exercise (like walking fast, running, jogging, dancing, swimming, biking, or other activities that cause a light or heavy sweat)?
2. On average, how many minutes do you engage in exercise at this level?

The first question has a categorical response option set (0–7 days), and the second question is recorded in blocks of 10 minutes, from 0–150 or greater. The two numbers are multiplied to display minutes per week of moderate-vigorous activity, which can also be converted into the three-category clinically useful variable: inactive, insufficiently active, or sufficiently active.

Compared with accelerometers, the Exercise Vital Sign is markedly easier to administer (more feasible) and is more practical for clinical settings. The two-question Exercise Vital Sign has adequate reliability for screening the physical activity level of a population (Coleman, 2012). In addition, a study shows that the Exercise Vital Sign measure has both good face and discriminant validity when used in EHRs (Coleman, 2012).

Accelerometers are sensors that detect motion and provide an objective measure of MET-minutes. They can be worn as a wristwatch and used to assess physical activity behavior over several days, and they can provide real-time feedback to users or clinicians. Although the use of these sensors in research studies is commonplace, there is a lack of standards for placement of the sensors, sampling frequency, and defining a valid "day." There are numerous devices available, including accelerometers embedded within smartphones. The validity of accelerometer assessment using smartphones requires more investigation; however, given their widespread availability, this research is likely to be done soon. Patient compliance can be a problem, and the cost of accelerometers presents another barrier to routine use in clinical settings.

Common Metric

Clinically relevant groupings of activity behaviors have been developed using METs as a measure of physical activity intensity. These include: light intensity defined as 1.1–2.9 METs; moderate intensity, defined as 3.0–5.9 METs, such as brisk walking or gardening; and vigorous intensity, defined as 6.0 METs or more, such as running or fast cycling (Physical Activity Guidelines Advisory Committee, 2008). The Centers for Disease Control and Prevention divides activity behaviors into low intensity (e.g., walking), moderate intensity (e.g., brisk walking), and high intensity (e.g., jogging) based on these MET classifications.

One approach for converting the Exercise Vital Sign measure into MET-minutes per week is to multiply the number of minutes spent in moderate-to-vigorous activity by 4.5 METs, which is the midpoint MET level for moderate activity. This computation provides a crude approximation of MET-minutes per week; however, it will underestimate values for individuals who spend more time in vigorous than in moderate activity.

Much scientific evidence linking physical activity with health benefits evaluates the number of MET-minutes per week in association with an outcome, such as rates of disease, biomarkers, or fitness levels. MET-minutes are the product of the MET level, which is based on the type of activity being performed and the duration of the behavior. Use of MET-minutes as a common metric allows different types of aerobic activities with different intensity levels to be related on a single scale.

Ratings of Measure by Committee

The Exercise Vital Sign is standard and freely available. Compared with accelerometers, the Exercise Vital Sign is markedly easier to administer (more feasible) and is more practical for clinical settings. Because of these considerations, the committee rated the measures as follows in Table 4-16.

TABLE 4-16 Ratings of the Measure for Physical Activity

Domain Measures	Standard Measure and Freely Available (*** = standard, * = no standard)	Usefulness (*** = most useful, * = least useful)	Feasible (*** = most feasible, * = least feasible)	Lack of Sensitive Information or Patient Discomfort (*** = least sensitive, * = most sensitive)	Committee Judgment of the Measure (*** = highest rating, * = lowest rating)
Exercise Vital Sign	***	***	***	***	***
Accelerometer	***	**	*	***	*

Limitations of Measures

Sedentary behavior was not reviewed as the measures and tools are not yet well developed.

Specific Populations

Accelerometry can be used among children and adolescents, and in research contexts, it has been used with infants. The Exercise Vital Sign has not been validated for pediatric populations, which is a topic for future research. Valid and reliable measures for geriatric populations exist to measure physical activity in older adults, but they were not prioritized by the committee owing to their lengthy forms. The health care team will need training on how to use these measures with people with disabilities or high-need patients (NIH, 2011).

Other Measures Reviewed

The International Physical Activity Questionnaire has a short form with nine questions. The committee reviewed this and found the measure to be acceptable, but it is more time consuming than the two-question measure.

Tobacco Use and Exposure

Tobacco use and tobacco-related illnesses are the leading cause of morbidity and mortality in the United States. Evidence strongly suggests that a health care provider's explicit interest in a patient's tobacco use can assist the patient taking steps toward stopping tobacco use. Tobacco use is a major cause of excess mortality among cancer-related deaths and is also a cause of heart disease, stroke, and chronic obstructive pulmonary disease (CDC, 2014c). The U.S. Preventive Services Task Force (USPSTF) recommends (A grade) that clinical care providers ask about tobacco use and provide tobacco cessation interventions for those who use tobacco products. Nicotine addiction has been studied intensely for more than 50 years. Nicotine contained in tobacco leads to dependence in many people. Based on the most recent 2012 National Health Interview Survey (NHIS) (CDC, 2014a), 18 percent of U.S. adults (18 years and older) are current cigarette smokers, while 21 percent were former smokers (Blackwell et al., 2014). The large majority of current smokers meet criteria for nicotine dependence.

Identifying tobacco-using persons is the first step to treatment. Practice guidelines from HHS and the American Psychiatric Association suggest asking patients at each visit whether they use tobacco. The tobacco use measure for Stage 2 Meaningful Use requires that more than 80 percent of all unique patients 13 years old or older seen by the eligible provider have smoking status recorded as structured data (CMS, 2012) with one of the following Systematized Nomenclature of Medicine (SNOMED) codes:

- Current every day smoker
- Current some day smoker
- Former smoker
- Never smoker
- Smoker, current status unknown
- Unknown if ever smoked
- Heavy tobacco smoker
- Light tobacco smoker

The ways in which tobacco counseling and treatment are handled by EHRs remains to be settled but was considered out of scope for this committee.

Identification and Description of Measure

Smoking status questions, lifetime and current, have been asked on the NHIS for almost half a century and are used to assess progress toward achieving the *Healthy People 2020* objectives. Although the questions have slightly changed throughout the years, the basis of measuring the prevalence of lifetime and current smoking status remains. The NHIS includes the following categories to measure if the patient is a current or every day smoker, former some day smoker, former smoker, or never smoker (Adsit and Fiore, 2013; ASPE, no date–a):

1. Have you smoked at least 100 cigarettes in your entire life?
   Yes No Refused Do not know, and if yes:
2. Do you NOW smoke cigarettes every day, some days or not at all?
   Every day Some days Not at all Refused Do not know

A "current every day smoker" or "current some day smoker" has smoked at least 100 cigarettes and still regularly smokes every day or periodically, yet consistently. A "former smoker" has smoked at least 100 cigarettes but does not currently smoke. A "never smoker" has not smoked 100 cigarettes. "Smoker, current status unknown" is known to have smoked at least 100 cigarettes, but whether they currently still smoke is unknown (Adsit and Fiore, 2013).

Common Metric

There is no common metric for tobacco use or exposure at this time.

Ratings of Measure by Committee

The smoking status measure is standard and freely available. Collecting this information in a systematic way in EHR is useful because smoking has been linked to many preventable diseases and is a major factor influencing life expectancy. The committee identified an additional measurement instrument that provides options to measure degree of dependence on nicotine and did not find the questions to be as sensitive in nature as other measures of dependency and thus considers them to be feasible to ask. Because of these considerations, the committee rated the measure as follows in Table 4-17.

Limitations of Measure

Occasional or intermittent smokers may be missed with these screening questions. The measure also is limited in only asking questions about cigarette use and does not ask about tobacco exposure (e.g., if patient lives with someone who smokes indoors). Also, the NHIS is used for ages 18 and above.

Specific Populations

Adolescents can be asked just one question because the first NIHS question may not identify those who have recently taken up smoking. A more appropriate question is taken from the Youth Risk Behavior Survey (ASPE, no date–b; Kann et al., 2014):

On how many of the past 30 days did you smoke a cigarette?
None   1–30 days   Refused   Do not know

For adolescents, cigarette smoking is defined as smoking cigarettes on at least 1 day during the 30 days before the survey. Pregnant women are a vulnerable population, but the committee concluded that the age-appropriate screening question(s) should be used as listed above.

Other Measures Reviewed

Other measures assess degree of dependence on nicotine. All have acceptably high levels of validity and reliability and have been shown to be

TABLE 4-17 Ratings of the Measure for Tobacco Use and Exposure

Domain Measure	Standard Measure and Freely Available (*** = standard, * = no standard)	Usefulness (*** = most useful, * = least useful)	Feasible (*** = most feasible, * = least feasible)	Lack of Sensitive Information or Patient Discomfort (*** = least sensitive, * = most sensitive)	Committee Judgment of the Measure (*** = highest rating, * = lowest rating)
NHIS Smoking Status Questions	***	***	***	***	***

useful in clinical assessment of the dimensions of a patient's dependence on nicotine. These measures are discussed below.

The National Survey on Drug Use and Health has both standard and modified versions; both measures are similar to the NHIS (Ryan et al., 2012). Longer measures are also available, such as the Tobacco Use Supplement to the Current Population Survey (TUS-CPS), which many consider a standard for complete information on national-, state-, and substate-level data from U.S. households regarding smoking, use of tobacco products, and tobacco-related norms, attitudes, and policies (NCI, 2013). The Nicotine Dependence Syndrome Scale (NDSS) (Shiffman et al., 2004), the Wisconsin Inventory of Smoking Dependences Motives (WISDM) (Piper et al., 2004), and the Fagerstrom Test of Nicotine Dependence (FTND) (Etter et al., 1999; Storr et al., 2005) create numeric scores that place the smoker on a range from low dependence to high dependence by focusing on endpoint definitions of dependence, such as heavy smoking, time to first cigarette in the morning, and smoking despite consequences. The Hooked on Nicotine Checklist (HONC) is well suited for use with smokers whose cigarette consumption is low, and it is a reliable and valid measure of diminished autonomy over tobacco (DiFranza et al., 2002).

The Tobacco Dependence Screener (TDS) is a self-report measure that assesses 10 DSM-IV tobacco dependence criteria (Piper et al., 2008). The FTND tends to yield better predictions of cessation outcomes than the NDSS, WISDM, or TDS. Research also shows that the NDSS and WISDM are more sensitive in detecting particular smoking motives (Piper et al., 2006). A single question can screen for smokers in population-based research: "Have you smoked one or more cigarettes in the past month?" (GEM, 2011). However, the committee concluded that the two-question measure aligned better with Meaningful Use SNOMED codes.

The Nicotine Dependence Scale for Adolescents (NDSA) is a six-question measure developed by the FTND and NDSS (NCI, 2012). The scale was designed primarily for survey research, thereby having limited clinical utility.

Alcohol Use

Alcohol is one of the most widely used substances in the world. Because it has both positive and negative health effects depending on type of use, measuring alcohol use involves measuring a continuum of risk. The USPSTF defines alcohol misuse as a variety of behaviors. Multiple validated and reliable measures exist for screening purposes. These measures address frequency of use and associated dependence.

Chapter 3 documents the association between alcohol misuse and adverse health effects. In making recommendations for screening for alcohol misuse and abuse, the committee believes that benefits gained in guiding patients toward safer alcohol use and/or into treatment for alcohol dependence outweigh the increased time required during a typical primary care encounter. Increased screening enables early intervention.

Identification and Description of Measure

Among multi-question scales measuring alcohol misuse and dependence that have acceptably high reliability and validity, the Alcohol Use Disorders Identification Test Consumption (AUDIT-C) is a three-question instrument, modified from the AUDIT 10-question instrument. It helps identify hazardous drinkers or those who have active alcohol use disorders (Bradley et al., 2007). This instrument is scored across a continuum from “no use” to “serious use,” and it has a different established norm for men and women. The higher the AUDIT-C score the more likely the patient’s drinking affects his or her health and safety.

The AUDIT-C has a sensitivity of 86 percent among patients with heavy drinking or dependence and a specificity of 72 percent (Bush et al., 1998). Cutoff scores greater than or equal to three on the AUDIT-C identify 90 percent of patients with active alcohol abuse or dependence and 98 percent of patients with heavy drinking (Bradley et al., 2007; Bush et al., 1998). This screening instrument appears to be practical for identifying active alcohol abuse or dependence (Bush et al., 1998). The three AUDIT-C questions are:

1. How often do you have a drink containing alcohol?
    a. Never
    b. Monthly or less
    c. 2–4 times a month
    d. 2–3 times a week
    e. 4 or more times a week
2. How many standard drinks containing alcohol do you have on a typical day?
    a. 1 or 2
    b. 3 or 4
    c. 5 or 6
    d. 7 to 9
    e. 10 or more
3. How often do you have six or more drinks on one occasion?
    a. Never
    b. Less than monthly
    c. Monthly
    d. Weekly
    e. Daily or almost daily

The questions are scored on a scale of 0 to 12: a = 0 points, b = 1 point, c = 2 points, d = 3 points, and e = 4 points. A score greater than 4 for men or 3 for women is considered to be heavy or hazardous drinking (Babor et al., 2001; Bradley et al., 2007).

Common Metric

While there is no common metric, the USPSTF has guidelines that could be followed regarding alcohol consumption.

Ratings of Measure by Committee

The AUDIT-C questions are freely available to administer in clinical settings, and it is a useful health tool in monitoring patients who are alcohol dependent or who have problem drinking behaviors. The AUDIT-C question takes approximately 1 minute to complete, making it feasible and practical for a patient to complete before a clinical visit. The committee does not believe this is a sensitive question for patients to answer. Because of these considerations, the committee rated the measure as follows in Table 4-18.

Limitations of Measure

If the response to this screen is rated as a positive indication of alcohol use or dependence, the care provider will need to use a more complete test to indicate the extent of the dependence and to refer the patient for appropriate care. Research using the CAGE and AUDIT measures in emergency department settings has shown their use to be feasible, yet they face several barriers owing to time demands and lack of resources to offer screening and brief interventions. Documenting problem drinking may equate to asking the patient to place in the record information contrary to their legal interest. The American College of Emergency Physicians offers a resource kit titled *Alcohol Screening and Brief Intervention Resource Kit* to their members, which provides information on the benefits of screening, facts about problem drinking, and templates on how to locate community resources (American College of Emergency Physicians, no date; Degutis, 1998; D'Onofrio and Degutis, 2004/2005).

Specific Populations

Screening for alcohol use and intervening with pregnant women is important and challenging (Chang, 2004). Women often alter their drinking patterns after they learn they are pregnant. Quantity and frequency questions on the screening instruments may not show the true risk of women

TABLE 4-18 Ratings of the Measure for Alcohol Use

Domain Measure	Standard Measure and Freely Available (*** = standard, * = no standard)	Usefulness (*** = most useful, * = least useful)	Feasible (*** = most feasible, * = least feasible)	Lack of Sensitive Information or Patient Discomfort (*** = least sensitive, * = most sensitive)	Committee Judgment of the Measure (*** = highest rating, * = lowest rating)
AUDIT-C	***	***	***	**	***

with high alcohol levels, a condition early in gestation likely to harm the fetus (Smith et al., 1987). Asking screening questions before pregnancy elicits more accurate measures of a woman's drinking behavior.

Federal and state prison populations typically show high rates of alcohol misuse, abuse, or dependency. Financial constraints of prison systems may play a role in the extent and quality of the intervention programs offered to those with positive screening results. Most states mandate screening and assessment of driving while intoxicated (DWI) offenses. Sentencing guidelines also recommend that all DWI offenders be screened for alcohol misuse/abuse. The screening instruments discussed above were not developed using prisoner populations nor were they tested in the context of the criminal justice setting. For example, offenders who may feel coerced into screening and treatment or fear being penalized (e.g., unfavorable terms of parole, loss of child custody) if they admit to their actual drinking behavior. Consequently, the validity of the screening results will be in question.

The AUDIT-C has been shown to provide reliable and valid assessment among adolescents ages 14 to 18 years old (Knight et al., 2003). For adolescents and young adults, attention should be given to any level of drinking as well as binge drinking.

Other Measures Reviewed

The committee reviewed several measures for alcohol use, including the single screening question, "On any single occasion during the past 3 months, have you had more than five drinks containing alcohol?," which can detect at-risk drinking and current alcohol use disorders (Fleming, 2004/2005; Taj et al., 1998). Administration of the single question in a primary care setting demonstrated a positive predictive value of 74 percent and a negative predictive value of 88 percent for problem drinking, with a sensitivity of 62 percent and specificity of 93 percent (Taj et al., 1998). However, the three-question AUDIT-C screen is more reliable in identifying problem drinking. The full 10-question AUDIT has established norms for indicating abuse and alcohol dependence. Scores of 8 or more are considered an indicator of harmful drinking, with a 92 percent sensitivity and 94 percent specificity (Babor et al., 2001). Although this instrument is viewed by many as being very accurate, it is also considered too time consuming in a health care setting because of its lengthy questions. The MAST 25-question instrument was not included because of its length. It was deemed impractical as an initial screening tool in a care setting. It remains an option for use in those screened positive using the single question or AUDIT-C. The CAGE four-question measure was also reviewed by the committee. The questionnaire identifies lifetime abuse or dependence, and most patients in whom alcohol abuse is detected are either actively addressing their substance abuse or are in recovery (American College of Emergency Physicians, no date; Degutis, 1998; D'Onofrio and Degutis, 2004/2005).

INDIVIDUAL-LEVEL SOCIAL RELATIONSHIPS AND LIVING CONDITIONS DOMAIN MEASURES

Social Connections and Social Isolation

Social relationships have been identified as a major psychosocial risk factor for health, and they have been identified as potential resources or buffers mitigating the impact of other risk factors for health, such as stress, and facilitating recovery from acute and chronic diseases (Cassel, 1976; Cobb, 1976). A voluminous body of research documents health effects of a range of social relationships (see review by Holt-Lunstad et al. [2010]), most notably social integration versus isolation (House, 2002), social support (Cohen and Syme, 1985; Uchino, 2009), and loneliness (Cacioppo et al., 2002). The committee considered the importance and relevance of the broad domain of social relationships for EHRs, focusing on the three subdomains just noted.

Identification and Description of Measure

Based on the recent meta-analytic review by Holt-Lunstad et al. (2010), the committee concluded that the updated and adapted Berkman-Syme Social Network Index could be adopted into EHRs. The index derived by Berkman and Syme (1979)—a four-question measure of social integration versus isolation (marital status, frequency of contact with other people, participation in religious activities, and participation in other club or organization activities)—showed an increase risk of all-cause mortality for individuals who were socially isolated. This result has been replicated (with few exceptions) in dozens of studies of broad community populations over more than three decades (e.g., reviews from House et al. [1988] and Holt-Lunstad et al. [2010], and most recently in the NHANES III [Pantell et al., 2013]). The Pantell et al. (2013) study found the mortality relative risks ranged from 1.5 up to 3.0 or higher for the most isolated (lowest quintile) compared to the rest of the population. These risks (and prevalence level for the high-risk category) generally equal or exceed those from cigarette smoking and a wide range of other major behavioral and biomedical risk factors for mortality. Each of the component questions in the measure has also been significantly predictive of all-cause mortality, though expectedly with lower relative risks. This measure has been similarly predictive of a wide range of specific causes of mortality and incidence and course of major diseases, especially cardiovascular disease.

The Berkman-Syme Social Network Index, and its scoring, have been appropriately constituted and used in the NHANES III survey. The questions are as follows[4] (Pantell et al., 2013):

1. In a typical week, how many times do you talk on the telephone with family, friends, or neighbors?
2. How often do you get together with friends or relatives?
3. How often do you attend church or religious services?
4. How often do you attend meetings of the clubs or organizations you belong to?

These categories form an ordinal scale that assesses the number of types of social relationships on which a person is connected and not isolated and has standard scoring. Individuals receive one point for each of the following: being married or living together with someone in a partnership at the time of questioning; averaging three or more social interactions per week (assessed with questions one and two, above); reporting attending church or other religious services more than four times per year (assessed with question three, above); and reporting that they belong to a club or organization (assess with question four, above). A score of 0 represents the highest level of social isolation and a score of 4 represents the lowest level of social isolation (Pantell et al., 2013). NHANES data can provide national norms for the data, and for their relation to a range of other psychosocial, behavioral, and biomedical risk factors.

These questions also have high relevance for clinical practice as they provide a picture of the social context in which patients live. Marital status, active participation in religious or other organizations, and regular informal contact with friends and family are resources that can help patients adhere to medical regimes, promote health behaviors and deter risky ones, provide avenues for health screening, and generally provide both structure and support in individuals' lives.

Common Metric

There is no common metric for social connection and isolation at this time.

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[4] Marital status information is collected in the demographic section of NHANES that includes the following options: married, widowed, divorced, separated, never married, and living with partner. Marital status is part of the scoring and not included in this list of questions. It will need to be adapted accordingly for patient self-reporting for use in EHRs.

Ratings of Measure by Committee

The four-question set is without copyright protections. On the basis of their strongly established relationship to health, potential value in clinical practice, ease of administration, and the lack of sensitive information that might cause patient discomfort, the committee has given this measure the following ratings, see Table 4-19.

Limitations of Measure

The committee did not identify any limitations in using the four-question measure.

Specific Populations

The suggested social integration versus isolation measure has demonstrated to be easily administered and strongly relates to health across the full range of the adult population. Such evidence is lacking for children, especially at younger ages. The social integration versus isolation measure for a child's parent or guardian may prove useful, as might measures of attachment and quality of relationship with parents or guardians. These are considered in other domains examined by the committee. Tools exist for geriatric populations to measure social isolation and disconnectedness, as older adults and those in worse health tend to experience greater levels of social isolation. However, the committee felt the four-question NHANES III measure was appropriate for use in all adults.

Other Measures Reviewed

Although similar evidence exists for the relation of measures of social support and of loneliness to health, it is not as strong and consistent as that for social integration versus isolation, nor is there as clearly a consensual measure that is easily administered (Holt-Lunstad et al., 2010; Steptoe et al., 2013). Both constructs, and measures of them, merit further consideration in future efforts to expand the inclusion of psychosocial factors in EHRs. Social contact via electronic media may emerge in the future as an additional aspect of social relationships.

Exposure to Violence

Interpersonal or domestic partner violence involves actual or threatened physical, sexual, psychological, or emotional abuse by a family member, caregiver, current or former spouse or partner, or dating partner. Inter-

TABLE 4-19 Ratings of the Measure for Social Connections and Social Isolation

Domain Measure	Standard Measure and Freely Available (*** = standard, * = no standard)	Usefulness (*** = most useful, * = least useful)	Feasible (*** = most feasible, * = least feasible)	Lack of Sensitive Information or Patient Discomfort (*** = least sensitive, * = most sensitive)	Committee Judgment of the Measure (*** = highest rating, * = lowest rating)
NHANES III Social Connections and Isolation Questions	***	***	***	***	***

personal violence can take many forms, including child and elder abuse and neglect and intimate partner violence. Assessment and management of child abuse and recording such information in the clinical record are a matter of law and will not be addressed specifically in this section. Intimate partner violence refers to the experience of being hit, slapped, pushed, or otherwise harmed by someone identified as a romantic partner. Elder abuse may be perpetrated by intimate partners, other family members—including someone's own children—as well as strangers. The USPSTF reviewed evidence related to violence against elders (USPSTF, 2012, 2013). Although mindful of the serious nature of elder abuse, the USPSTF found insufficient evidence linking improved health outcomes to routine assessment of elders for exposure to violence. The USPSTF did, however, recommend screening for intimate partner violence, but only for women of reproductive age.

Identification and Description of Measure

Despite strong evidence of the links between interpersonal violence and health, existing recommendations for screening are limited to intimate partner violence screening of women in childbearing years, following the USPSTF recommendation. Thus the committee limited its discussion of metrics and measures to intimate partner violence.

Intimate partner violence, a subdomain of interpersonal violence, refers specifically to violence within romantic relationships. Intimate partners can be of the same or the opposite sex (CDC, 2006b). The National Intimate Partner and Sexual Violence Survey documented that one in three women have experienced physical violence (Black et al., 2011). Intimate partner violence is associated with life-threatening injuries as well as long-term physical and mental health problems, and it may account for 20 percent of all homicides (de Boinville, 2013). Intimate partner violence has been implicated as a chronic stressor leading to substance abuse, depression, and other mental health problem. Health care costs are generally higher for those experiencing intimate partner violence, and undetected and untreated intimate partner violence can lead to poor health outcomes.

Screening for intimate partner violence in health care settings is one of the eight preventive health services now covered in new health plans without requiring a copayment, coinsurance, or deductible[5] (HRSA, 2012). However, screening recommendations remain inconsistent across various health organizations and agencies. As noted above, the USPSTF calls for clinicians to screen women of childbearing age and offers no recommendations regarding assessment of women outside of this age range or for men. The American College of Gynecologists recommends screening of all

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[5] The Patient Protection and Affordable Care Act, Public Law 111-148 § 2713.

women (ACOG, 2012), while the World Health Organization (WHO) recommends against universal screening for any women (WHO, 2013). Screening for intimate partner violence is believed to have positive outcomes if the health provider has the ability to provide for or refer to interventional services.

At this time there is not a screen that has well-established psychometric properties (Rabin et al., 2009); nonetheless, it is important to screen women (IOM, 2011a) of reproductive age. Successful implementation of broad-based intimate partner violence screening rests in part on the ability to provide for or refer to interventional services (McCaw, 2013). The committee reviewed the HARK (Humiliation, Afraid, Rape, Kick), which is a four-question self-reported instrument that represents different components of interpersonal violence, including emotional, sexual, and physical abuse (Sohal et al., 2007). The questions are:

1. Within the last year, have you been humiliated or emotionally abused in other ways by your partner or ex-partner?
   Yes No
2. Within the last year, have you been afraid of your partner or ex-partner?
   Yes No
3. Within the last year, have you been raped or forced to have any kind of sexual activity by your partner or ex-partner?
   Yes No
4. Within the last year, have you been kicked, hit, slapped, or otherwise physically hurt by your partner or ex-partner?
   Yes No

Each question answered with a yes is a score of 1. Scores then can range from 0 to 4. The sensitivity of the optimal clinical cutoff score of one or more was 81 percent and the specificity is 95 percent (Nelson et al., 2012).

Common Metric

There is not a common metric for intimate partner violence at this time.

Ratings of Measure by Committee

The clinical questions are freely available. This four-question screen is clearly useful for clinical interventions, especially because this domain is linked to long-term health outcomes. The committee deemed this domain highly sensitive, noting the strong evidence of shame and desire to avoid reporting violence due to perceptions of increased risk (IOM, 2011a). Other concerns include unanticipated disclosure that could occur from the inadvertent distribution of an after-visit summary, and potential provider-based prejudice emerging from knowledge of a past history of abuse. Because of these considerations, the committee rated the measure as follows in Table 4-20.

Limitations of Measure

Limitations for this measure include that it is highly sensitive information potentially causing patient discomfort, and the narrow focus of intimate partner violence, rather than a larger lens of interpersonal violence. Another limitation may be for health care providers who lack experience in screening and follow-up interventions that are necessary for improved outcomes (IOM, 2011a).

Specific Populations

The USPSTF neglected to extend the recommendations for screening to women over the age of 46 or to men. Some writers (Connelly et al., 2000) posit the need for additional intensive screening for women with high-risk pregnancies.

Immigrant women may be hesitant to report intimate partner violence because of differences in cultural perceptions or for fear of deportation (Committee on Health Care for Underserved Women, 2012).

Adolescent females are a population that has reported experiencing physical dating violence (Silverman et al., 2004); however, assessments of intimate partner violence for adolescents or children are not currently available.

Other Measures Reviewed

The committee reviewed other assessments of risk of violence; however, most lacked standards for validity. The committee also reviewed instruments specific to perpetrators (e.g., The Violence Risk Scale [Olver et al., 2014]—sexual offender version—and the Historical, Clinical and Risk management-20 [HCR 20]); however, their validity and reliability to predict violence remains to be determined (Dolan and Doyle, 2000). According to the USPSTF, in addition to HARK there are five intimate partner violence screening tools with good sensitivity and specificity (USPSTF, 2012): Hurt, Insult, Threaten, Scream (HITS) (English and Spanish versions); Ongoing Abuse Screen/Ongoing Violence Assessment Tool (OAS/OVAT); Slapped, Threatened, and Throw (STaT); Modified Childhood Trauma Questionnaire–Short Form (CTQ-SF); and Woman Abuse Screen Tool (WAST). The HITS instrument includes four questions, can be used

TABLE 4-20 Ratings of the Measure for Exposure to Violence

Domain Measure	Standard Measure and Freely Available (*** = standard, * = no standard)	Usefulness (*** = most useful, * = least useful)	Feasible (*** = most feasible, * = least feasible)	Lack of Sensitive Information or Patient Discomfort (*** = least sensitive, * = most sensitive)	Committee Judgment of the Measure (*** = highest rating, * = lowest rating)
HARK	***	***	**	*	***

in a primary care setting, and is available in both English and Spanish. It can be self- or clinician-administered. STaT is a three-question self-report instrument that was tested in emergency department settings. All assess current or past exposure rather than risk of future exposure. The USPSTF found no risk inherent in the screening, and modest positive gains in safety, health, and injury mitigation arising from early intervention (USPSTF, 2012). Another measure reviewed by the committee was a two-question screener recommended by the Committee on Health Care for Underserved Women (2012), but it lacked a clinical cutoff.

NEIGHBORHOODS AND COMMUNITIES DOMAIN MEASURES

Neighborhood and Community Compositional Characteristics

A large body of work has used measures of neighborhood socioeconomic characteristics to investigate the impact of neighborhood contexts on health (Diez-Roux and Mair, 2010). Neighborhood measures have also been used as proxies for individual-level socioeconomic information when it is not available. Area socioeconomic characteristics are derived from various summary measures of the compositional characteristics of neighborhoods and communities that can be created from routinely collected census data. The "areas" for which these measures can be calculated are many, but census tracts are one of the ones most commonly used as proxies for residential neighborhoods. Examples of measures include median household income; percent below poverty; the percent of persons who have graduated college; the percent of persons in managerial, professional, or executive occupations; and the unemployment rate. Various summary measures of "area socioeconomic position," derived theoretically or using techniques such as factor analysis, have been created (Diez-Roux and Mair, 2010). Neighborhood and community compositional characteristics, such as area socioeconomic measures, have been shown to be related to various health outcomes. Even though individual-level characteristics have a stronger association with health outcomes than do neighborhood characteristics, there is an independent contribution of neighborhood and community compositional characteristics above and beyond individual factors (Diez-Roux and Mair, 2010). Neighborhood and community compositional characteristics have also been shown to be useful in predicting health risk (Fiscella and Franks, 2001; Fiscella et al., 2009; Kim et al., 2010; Pollack et al., 2012; Vortuba and Kling, 2008) and outcomes of care for individual patients (Gerber et al., 2010). Recent work has also employed these measures in health services research (Nagasako et al., 2014).

In Chapter 3 (part of Phase 1), the committee considered race/ethnicity composition of an area as a domain under neighborhood and community compositional characteristics. For this chapter (part of Phase 2), which focuses on the measures, the committee opted to focus on area socioeconomic geocodable (defined in the following section) measures and not on race/ethnic composite of an area because race/ethnicity of an individual patient is routinely collected in EHRs.

Identification and Description of Measure

To characterize neighborhood and community compositional characteristics (such as area SES) for a patient's residential address, information needs to be obtained. This information must be collected in a standardized manner so residential addresses can then be "geocoded." Geocoded residential addresses have geographic identifiers—latitude and longitudinal coordinates—attached to census codes. Once geocodes are available the location can be linked to geographically referenced data from the American Community Survey (ACS) to characterize area socioeconomic characteristics. The geocodes can also be used to link locations to various sources of neighborhood contextual characteristics, including measures of spatial access to resources, air pollution data, crime rates, or measures of the built environment—for example, walkability score (Philadelphia Department of Public Health, 2013; TRB and IOM, 2005; WHO, 2011). The committee prioritizes the physical environment, and as more geocodable data become available and can be linked to census data (i.e., economic or occupation indicators or measures of racial/ethnic composition) as well as measures created through other linkages to other data (i.e., population health surveys), this type of data linking can occur. This information may also be linked to geocoded patient data providing a demographic neighborhood and community profile of the patient's living conditions.

The ACS provides data on the median household income for various census tracts (U.S. Census Bureau, 2014a). Median household income is a continuous measure that can be used to capture variability across areas. Because census tracts were at least initially defined to be approximately homogeneous in socioeconomic characteristics, and because they are used in many analyses as proxies for neighborhoods, the committee suggests using census tract measures. The median household income measured in current U.S. dollars at the level of the census tract can serve as the standard measure for this domain. In addition, because the ACS is carried out only on a sample of households each year, the committee suggests pooling the data across multiple years to obtain the estimates for income, with the number of years serving as a function of the sample size per year in any given tract.

Geocoding a patient's residential address takes the attributes of a street address, compares them to a database of addresses in a geographic information system (GIS), and assigns coordinates based on the best match

(CA.gov, 2014). The four-digit extension is added on via program coding. An example of how to collect patient address in a standard way is listed below:

- House Number + Directional (such as North, South, etc.) + Street Name
- City
- State
- Zip Code + 4-digit extension

Common Metric

There is not a common metric for neighborhood and community compositional characteristics at this time.

Ratings of Measure by Committee

Geocodable patient address and census tract-median household income are neighborhood indicators that can be useful when systematically included in the EHR. The measures are standard and easy to obtain in a systematic way from the ACS; they are useful at a population and a clinical level (especially in a context where individual-level income data are unlikely to be available); they are feasible; and providing an address to enable geocoding and the resulting census-tract information is not sensitive. Because of these considerations, the committee rated the measures as follows in Table 4-21.

Limitations of Measure

Collecting a patient's residential address in a standardized way is necessary for the geocodable data to be linked to the patient's record. For patients who move often or are without stable and permanent housing, this could be difficult. Another limitation is that in order for geocoding to work, it must be completely standardized. Geocoded addresses that are not properly formatted or collected will lack accuracy if addresses are coded using only zip codes (Rushton et al., 2007). Zip codes are not geographic areas and do not have exact spatial bounds. As such, there is no real correlation between zip codes and census geography; thus, statistical analyses are conducted to estimate zip code populations associated with health outcomes (CA.gov, 2014).

Specific Populations

Median household income by census tract is relevant for all age groups. Other neighborhood characteristics such as proximity to schools and play-

TABLE 4-21 Ratings of the Measure for Neighborhood and Community Compositional Characteristics

Domain Measures	Standard Measure and Freely Available (*** = standard, * = no standard)	Usefulness (*** = most useful, * = least useful)	Feasible (*** = most feasible, * = least feasible)	Lack of Sensitive Information or Patient Discomfort (*** = least sensitive, * = most sensitive)	Committee Judgment of the Measure (*** = highest rating, * = lowest rating)
Geocoded Residential Address	***	***	***	***	***
Census Tract-Median Household Income	***	***	**	***	***

grounds may be particularly relevant for children; environmental exposures may be particularly relevant to individuals with asthma or other respiratory ailments; and the age structure and proximity to pharmacies and health care may be particularly relevant to older individuals.

Other Measures Reviewed

A wealth of other physical and social environment data can be linked to geocoded address information. Measures of land use, urban design, and walkability include measures such as the extent to which an area includes residential and other (commercial or retail) uses, proximity to various types of uses (e.g., shops, social destinations), whether street networks are interconnected in ways that allow easy transportation by walking, and other features of design such as the presence of sidewalks that may encourage or detract from walking for transportation or leisure. These measures can be calculated using a GIS in conjunction with routine and specially collected geographically referenced data. Summary measures (such as the walkability score) that combine information from several of these domains have also been created. Access to resources such as healthy foods and recreational facilities can also be characterized using a GIS, as can environmental exposure data, such as levels of air pollutants or proximity to highways or hazardous sites. Geocoded address data can also be linked to crime data, when available, at a disaggregated data level or to other survey data that can be used to characterize constructs such as social capital and social cohesion or levels of safety for neighborhoods.

Although all these measures have potential clinical and population usefulness, the data required to create them is not routinely available in a standardized format. In addition, the processes used to create the measures can be complex, and a number of different measures exist. The validity and usefulness of different types of measures remains a topic of active research. For this reason the committee does not suggest the inclusion of any specific measures of these neighborhood contextual domains in the EHR at this point.

However, it is expected that the availability of geocode information in the EHR will stimulate further research on the value of these measures and may justify including additional measures in the EHR in a systematic way in the future. The committee hopes that in the future, variables related to compositional characteristics of the neighborhood and measures reflecting contextual characteristics, such as hazards and resources in the physical and social environment, will be standardized and routinely collected and thus able to be linked to all patient records.

SUMMARY OF CANDIDATE DOMAIN MEASURES REVIEWED BY THE COMMITTEE

A summary of the candidate domains and the related measures that were reviewed are shown in Table 4-22.

TABLE 4-22 Summary of All Domain Measures with Committee Ratings

Domains and Corresponding Measures	Standard Measure and Freely Available (*** = standard, * = no standard)	Usefulness (*** = most, * = least)
Sexual Orientation		
Self-Identity (1 Q)	***	*
Sexual Behavior (1 Q)	***	**
Race and Ethnicity		
U.S. Census (2 Q)	***	***
OMB Definition (2 Q)	***	**
Country of Origin/ U.S. Born Versus Non-U.S. Born		
U.S. Census (2 Q)	***	**
Education		
Educational Attainment (2 Q)	***	***
Employment		
MESA Employment Question (1 Q)	**	**
Financial Resource Strain		
Overall Financial Resource Strain (1 Q)	***	***
Food Insufficiency (1 Q)	***	**
Housing Insecurity (1 Q)	*	*

Feasible (*** = most feasible, * = least feasible)	Lack of Sensitive Information or Patient Discomfort (*** = least sensitive, * = most sensitive)	Committee Judgment of the Measure (*** = highest rating, * = lowest rating)
***	**	**
***	*	**
***	***	***
***	***	***
***	*	**
***	***	***
***	**	**
***	**	***
**	**	***
*	*	*

continued

TABLE 4-22 Continued

Domains and Corresponding Measures	Standard Measure and Freely Available (*** = standard, * = no standard	Usefulness (*** = most, * = least)
Health Literacy		
Chew et al. (2004) (3 Q)	***	*
Stress		
Adverse Childhood Experiences (ACE) (11 Q)	***	*
Elo et al. (2003) (1 Q)	***	***
Depression		
Patient Health Questionnaire (PHQ)-2 (2 Q)	***	***
PROMIS-8b (8 Q)	***	*
Anxiety		
GAD-7 (7 Q)	***	**
PROMIS-7a (7 Q)	***	**
Conscientiousness		
Big Five Inventory-10 Item (1 Q)	*	**
Patient Engagement/Activation		
PAM	*	*
Optimism		
Life Orientation Test-Revised (6 Q)	***	**
Self-Efficacy		
Self-Efficacy Scales for Specific Behaviors	*	*
NIH Toolbox (10 Q)	***	*

Feasible (*** = most feasible, * = least feasible)	Lack of Sensitive Information or Patient Discomfort (*** = least sensitive, * = most sensitive)	Committee Judgment of the Measure (*** = highest rating, * = lowest rating)
***	**	*
**	*	*
***	**	***
***	**	***
**	**	*
***	**	**
***	**	**
*	***	*
**	***	*
***	***	**
*	***	*
***	***	*

continued

TABLE 4-22 Continued

Domains and Corresponding Measures	Standard Measure and Freely Available (*** = standard, * = no standard	Usefulness (*** = most, * = least)
Dietary Patterns		
Fruit and Vegetable Consumption (2 Q)	***	**
Physical Activity		
Exercise Vital Sign (2 Q)	***	***
Accelometer	***	**
Tobacco Use and Exposure		
NHIS Smoking Status Questions (2 Q)	***	***
Alcohol Use		
AUDIT-C (3 Q)	***	***
Social Connections and Social Isolation		
NHANES III (4 Q)	***	***
Exposure to Violence		
Intimate Partner Violence: HARK (4 Q)	***	***
Neighborhoods and Communities Compositional Characteristics		
Geocoded Residential Address	***	***
Census Tract-Median Household Income	***	***

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Feasible (*** = most feasible, * = least feasible)	Lack of Sensitive Information or Patient Discomfort (*** = least sensitive, * = most sensitive)	Committee Judgment of the Measure (*** = highest rating, * = lowest rating)
***	***	**
***	***	***
*	***	*
***	***	***
***	**	***
***	***	***
**	*	***
***	***	***
**	***	***

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5

Recommended Core Domains and Measures

During its foundational work (Chapters 1–4), the committee considered each domain *individually*. To recommend core measures of social and behavioral domains for inclusion in all electronic health records (EHRs), the committee sought to identify a parsimonious panel of measures that would be complete, interoperable, and efficient. To do so, it stepped back and considered overlap and interaction of domains. The stability of measures was also considered. The former considerations inform which combination of domains provides the best coverage of major determinants of health, while the latter informs how frequently the domains need to be assessed. The committee considered the suitability of available measures, first individually as described in Chapter 4, and then relative to one another as described in this chapter. Finally, the committee used a consensus process to construct a coherent panel and agree on recommended core measures.

OVERVIEW OF THE CANDIDATE DOMAINS

This section presents an overview of the candidate domains, organized by the levels in the committee's conceptual outline presented in Chapter 2 (see Table 2-1). Table 5-1 summarizes the needed frequency of assessment as well as the ways that information about the domains might be used for direct patient care, by health systems and public health entities, and how it might be used by researchers.

The domains differ in their stability over a person's life course. Sociodemographic characteristics of the person, which have implications for an individual's resources and adverse exposures, are relatively unlikely to

TABLE 5-1 Candidate Domains Organized by Levels and Suggested Frequency of Assessment

Level	Domain	Frequency of Assessment	Examples of Use in Direct Care of Patient	Examples of Use by Health System or Public Health	Examples of Use in Research to Test
Sociodemographic	• Race and ethnicity • Country of origin • Education • Employment • Financial resource strain ▪ General ▪ Food insecurity • Health literacy • Sexual orientation ▪ Identity ▪ Behavior	• At entry • At entry • At entry • Screen and follow up • Screen and follow up • Screen and follow up • At entry • Screen and follow up • Screen and follow up	• Reduce risk level associated with few resources	• Service planning • Characterize population	• Identify high-risk groups • Interaction with census-tract variables
Behavioral	• Dietary patterns • Physical activity • Tobacco use and exposure • Alcohol	• Screen and follow up for all these domains	• Reduce risk behavior via prescriptions, referral, motivational interviews	• Quality measure (rate of risk behaviors) • Address obstacles (e.g., gym access)	• Mediating role in disparities • Interaction with genetics • Best ways to change behavior in subgroups
	• Stress: ▪ General ▪ Childhood history (ACES) • Negative mood and affect	 • Screen and follow up • At entry	• Take into account literacy in management of patients • Reduction in risk level	• Service planning • Characterize population	• Direct effects on disease onset, progression, and response to treatment

Psychological	▪ Depression ▪ Anxiety • Psychological assets ▪ Conscientiousness ▪ Patient engagement/ activation ▪ Optimism ▪ Self-efficacy	• Screen and follow up • Screen and follow up • At entry • By condition • At entry • By condition	• Setting goals for care • Stress management		• Interaction with genetic factors • Best ways to increase assets
Individual-Level Social Relationships and Living Conditions	• Social connections and social isolation • Intimate partner violence	• Screen and follow up for these domains	• Reduce risk level (e.g., social work linkage to senior centers, support groups) • Benefit of group visits	• Service planning (e.g., programs to engage socially isolated individuals)	• Direct effects on disease onset, progression, and response to treatment • Interaction with genetic factors
Neighborhoods and Communities	• Patient address • Use address to geocode median household income and racial/ ethnic composition (census-tract)	• Verify every visit • Update on address change	• Identify individual's access to resources and exposure to hazards	• Identify resources and hazards affecting populations	• Role of built and social environment on health behaviors and on disease onset and progression

change, especially once one reaches adulthood. Other risk factors are more fluid. Although some health behaviors are habitual, they may fluctuate on their own or in response to an intervention or treatment. Social relationships and affective states are likely to vary over time and with changing circumstances.

The stability of a domain affects the frequency with which it needs to be assessed for various uses. A stable domain (e.g., race and ethnicity) can be assessed once at entry; others (e.g., depression) require periodic screening with detailed assessment and follow-up on a positive screen. Still others (e.g., residential address) require verification at every visit. Frequency of assessment is a factor in evaluating the feasibility of including a measure of the domain in EHRs; a detailed assessment may be feasible if needed only at entry, but not if needed frequently. Similarly, domains that can be assessed with a brief screen with targeted follow up are more feasible than are in-depth assessments that need to be repeated.

The use of social and behavioral information made accessible in the EHR varies by level and domain. Assessing the risk associated with the patient's profile should inform diagnosis and enable more effective treatment plans that set goals with patients for promoting health and reducing disability that take into account the patient's social context, behaviors, and psychosocial risks (HealthIT.gov, no date). For some domains, interventions are already available for those identified at risk (e.g., stress management programs for those under chronic stress or cognitive behavioral therapy for depressed patients). However, acting on other domains will require the development and testing of efficient, cost-effective interventions. Public health entities and health systems should find the committee's identified domains and measures useful for planning their services and characterizing their populations. Researchers can use the information to inform the design of interventions to (1) reduce health-damaging behaviors, attitudes, and emotional states; (2) to increase health-promoting ones; and (3) to address adverse social conditions.

Knowledge of social and behavioral determinants of health is useful in all clinical settings. Most frequently this information will initially be collected in primary care settings or by practitioners who have had a long-term relationship with the patient. Where there are large integrated health care delivery systems, multispecialty centers, or effective health information exchange, this information will be available to all practitioners in the system without the need to recollect data. Because of the current limits of interoperability across systems, many practitioners outside of an integrated system will not have the benefit of knowledge of their patients' social and behavioral risks and resources unless they collect it themselves. Because these determinants may be important in the evaluation and treatment of problems seen by specialists (e.g., abdominal pain, headaches) as in primary care, the committee believes that health care professionals at all sites should have the ability to collect and add information to the EHRs in order to best treat and care for the patient.

In Chapter 6, the committee provides a more robust description of both the benefits and the challenges for a variety of stakeholders in obtaining the recommended social and behavioral information in the EHR. The levels in Table 5-1 reflect consideration of the processes that serve as pathways connecting domains at each level with "downstream" determinants of health. These processes are part of the conceptual models described in Chapter 2; they guided the committee's work but were not explicitly identified and reviewed in detail as part of the committee's charge. However, it is worth noting that the direct and indirect pathways connecting some domains to health have been subject to extensive scientific investigation, whereas other domains remain to have the key processes identified. Perhaps most proximal to health are the identified behavioral domains, which directly affect biological pathways affecting disease onset and progression. For example, smoking cigarettes harms nearly every organ in the body, making smoking the leading preventable cause of death in the United States (CDC, 2014). Health-related behaviors are, however, shaped by the more "upstream" domains whose effect on health may be direct and may be partially mediated by behavioral risks. For example, the likelihood that someone smokes is affected by the rates of smoking of those in her or his community, social norms about smoking, and policies such as taxation of tobacco products (IOM, 2011). Psychological domains may also have a direct effect on pathophysiological processes. For example, stress can elicit alterations in the sympathetic nervous system and the hypothalamic pituitary adrenal system, influencing inflammation, cellular aging, and immune function (Hawkley and Cacioppo, 2004; Smith and Vale, 2006). Psychological domains, such as optimism or conscientiousness, may also contribute to a patient's desire or ability to carry out a prescribed treatment.

SUITABILITY OF THE MEASURES

Chapter 4 describes the process the committee used to evaluate the suitability of individual measures of each of the candidate domains for inclusion in all EHRs or for specific populations. The committee's rating of each measure on four criteria and the overall committee judgment of the priority of including the measure in EHRs are summarized in Chapter 4. The four criteria can be collapsed into two dimensions reflecting the *readiness* of a measure for use in the EHR and the *usefulness* of having the information in the patient record for clinical, population management, and research purposes. Figure 5-1 displays all the measures the committee rated across these two dimensions.

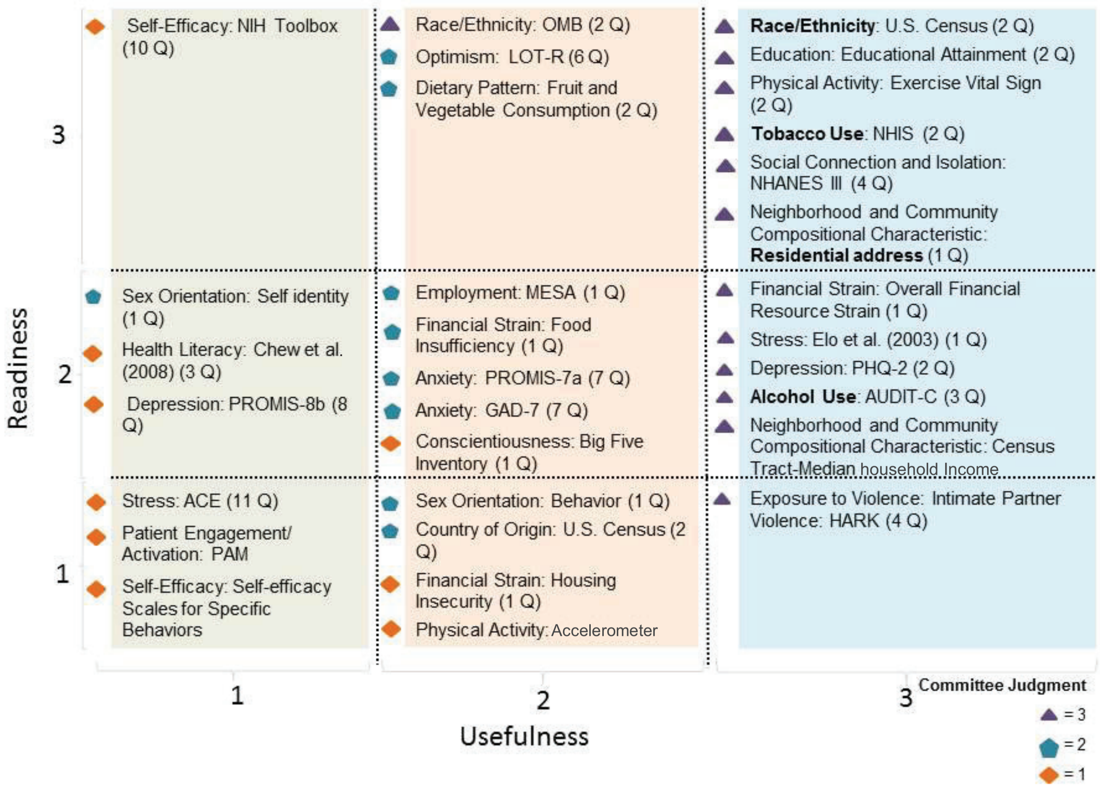

FIGURE 5-1 Standard domain measures by usefulness, minimum readiness, and committee judgment.
NOTE: Q = question(s); bolded items = measures routinely collected.

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The readiness axis reflects the ease of obtaining and storing information on a given domain; this is affected by the availability of a standard, freely available measure; the feasibility of attaining the information; and how sensitive the information is to collect. Readiness was quantified by taking the *minimum* of the committee's ratings (1 = low, 3 = high) reported in Chapter 4 for any of the three criteria (availability of a standard measure, feasibility, and lacks sensitive information or causes patient discomfort). The committee considered using the average of those ratings. However, a weakness in any of these three criteria engendered caution about the readiness of a measure because a higher rating on one criterion does not offset weakness on another. Use of the minimum rather than the average score produced a graph more consistent with the committee's overall judgment.

The usefulness axis was quantified by the committee rating (1 = low, 3 = high) of the usefulness of the information on that measure in the EHR for improving health outcomes reflecting broad applicability and usefulness in clinical settings. Figure 5-1 arrays where each measure falls on the committee judgment (low, moderate, high) and on two dimensions (usefulness and readiness). The symbol in front of each measure (◆ lowest priority, ⬟ medium priority, ▲ highest priority) represents the committee's overall judgment of priority of including the measure in the EHR. The items bolded are domains that are routinely collected in EHRs.

Different measures of the same domain sometimes received different degrees of endorsement in usefulness and readiness. For example, a two-question screening measure (PHQ-2) on depression was rated as highly useful and highly feasible while the PROMIS-8b depression scale, which is longer and more useful for monitoring change in symptoms over time than as an initial screener, received lower ratings for feasibility and usefulness in all EHRs. Not surprisingly, measures in the upper-right quadrant (most favored on usefulness and on readiness) had the strongest endorsement from the committee members while those in the lower-left quadrant (least favorable on usefulness and readiness) were rated the lowest. Figure 5-1 makes clear that the committee placed more emphasis on overall rating on the usefulness of the data provided by a measure than on its readiness.

CONSTRUCTING A PANEL OF MEASURES

The committee's statement of task included identifying the specific measures of social and behavioral determinants of health that should be included in all EHRs. In addition to identifying individual measures with the most favorable combination of usefulness and readiness, the committee aspired to construct a coherent panel that, taken together, would minimize overlap and fill gaps in knowledge about patients and populations. Rather than maximizing the usefulness of each individual measure, an ideal panel aims to identify a small set of measures that are easily implemented, are broadly applicable, are not redundant, and are representative of patients' psychological and social states.

The term *social vital sign* has been used in the past primarily to indicate the social health of a population rather than that of an individual (Eichberg and Petry, 2009). The committee makes direct analogy between the physiologic vital signs and the psychosocial vital signs intending to create a parsimonious panel of characteristics that are easy to measure and broadly applicable to all individuals.

Physiological vital signs are readily accessible measures of a patient's physiologic state. Traditionally, they have included body temperature, blood pressure, weight, heart rate, and respiratory rate. While one can imagine numerous other measures of the physiologic state, this small set can be measured quickly and accurately, and it provides a deep view of the patient's physiological status that is relevant to most patients. Over the years, most diseases have come to be characterized in terms of vital signs because they are generally available.

For at least half a century, a set of social characteristics have also been collected during routine clinical evaluations and recorded in the chief complaint and social history sections of the clinician's note (Delbanco et al., 2010). They generally include race (usually mixed with ethnicity), occupation, marital status, living situation, use of alcohol, use of tobacco, and recent unusual travel. This set is a starting point in the sense that many years of experience led to its creation. Nevertheless, evidence is lacking from the literature that any given set is the correct one and is clearly beneficial. Future research can test the usefulness of a coherent panel of "psychosocial vital signs" for diagnosing and treating various conditions as well as the contribution of single indicators.

Creating a parsimonious panel of recommended measures does not detract from the importance of measures that were not included. To the contrary, the others may also be useful in EHRs. The small panel tends to favor measures that are broadly applicable and important (and therefore are considered most useful), such as screening tools for important and common clinical conditions like alcohol abuse, tobacco use, and depression. A broader variety of measures are useful for less common conditions for which a minority of patients require screening and for monitoring progress of treatment on conditions that were previously screened. While these measures might not be presented for every clinical encounter or for every type of care provider, identifying standard measures that could be included in EHRs and collected as needed will still be useful (e.g., monitoring progress in depression treatment). The definition of a small panel does not detract from the definition of a more comprehensive panel for special cases or settings where a more detailed social assessment is indicated. Table 5-2

TABLE 5-2 The Committee's Analytic Process in Narrowing Domains and Measures to a Parsimonious Measurement Panel

Process Steps	Method	Results
Conceptual Framework Analysis	Integrate models relevant to SBD of health (Figures 2-1 to 2-4)	5 Levels
Domain Identification	From extensive list of SBD concepts identified domains for consideration (Table 2-1)	31 Domains
Candidate Domains Selection	Applied criteria: strength of association with health; and clinical, population health, and research usefulness	17 Domains
Measure Identification	Domain workgroups conducted literature reviews of measures Measure set identified based on psychometric properties	17 Domains/31 Measures
Parsimonious Measurement Panel Construction	Applied criteria: readiness (standard measure, feasibility, lack of sensitive information); usefulness for inclusion in the EHR; and overall committee judgment	11 Domains/12 Measures

NOTE: EHR = electronic health record; SBD = social and behavioral determinants.

presents the committee's analytic process, summarizing its efforts to reach its recommendations of which measures the committee identified as having high priority for inclusion in all EHRs.

What follows are the committee findings and recommendations regarding measures for inclusion.

COMMITTEE FINDINGS AND RECOMMENDED CORE DOMAINS

Finding 5-1: Four social and behavioral domains of health are already frequently collected in clinical settings. The value of this information would be increased if standard measures were used in capturing these data.

> **Recommendation 5-1: The Office of the National Coordinator for Health Information Technology and the Centers for Medicare & Medicaid Services should include in the certification and meaningful use regulations the standard measures recommended by this committee for**

> **four social and behavioral domains that are already regularly collected: race/ethnicity, tobacco use, alcohol use, and residential address.**

Finding 5-2: The addition of selected social and behavioral domains, together with the four domains that are already routinely collected, constitute a coherent panel that will provide valuable information on which to base problem identification, clinical diagnoses, treatment, outcomes assessment, and population health measurement.

> **Recommendation 5-2: The Office of the National Coordinator for Health Information Technology and the Centers for Medicare & Medicaid Services should include in the certification and Meaningful Use regulations addition of standard measures recommended by this committee for eight social and behavioral domains: educational attainment, financial resource strain, stress, depression, physical activity, social isolation, intimate partner violence (for women of reproductive age), and neighborhood median-household income.**

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6

Implementation Issues

In Chapter 1, the committee defines the electronic health record (EHR) as the electronic version of the patient health record, and the EHR system as both the database of that information and the tools used in various workflows to collect the information and support decision making and analysis. The addition of the recommended panel of social and behavioral measures to the EHR has implications for workflow changes to collect and review the new information and for workflow changes needed to address the problems surfaced through these measures. Both types of changes will require modifying how clinical teams operate and how patients report on their own experiences and engage in health-relevant behaviors; however, those details are beyond the scope of this study.

In addition to the challenges that surface when adding any new data to the EHR (particularly the time needed to obtain information), some challenges are specific to the addition of social and behavioral data. Responsibility for addressing social and behavioral determinants of health that surface as problematic in the EHR generally fall outside of the traditional health care system. However, to the degree that addressing these determinants reduces near-term health care utilization, such as hospital readmissions, as well as improves health and reduces future health care service utilization, the investment of time and resources will be well worth it. This chapter describes some of the anticipated challenges, suggests ways to overcome these challenges, and identifies offsetting benefits of implementing the panel of recommended measures. While some of the barriers will be difficult to resolve, case studies have been included to illustrate successful experiences of implementation.

CHALLENGES TO ADDING *ANY* DATA TO EHRS

Although EHRs have great potential to improve quality, coordination, safety, health outcomes, and overall efficiency in health care, many obstacles exist in fully realizing their potential (IOM, 2012). A systematic review identified eight categories of barriers to physician adoption of EHRs: financial, technical, time, psychological, social, legal, organization, and change process issues (Boonsta and Broekhhis, 2010). The review suggests that it is valuable for hospital managers, project leaders, and change managers to understand which of these are of greatest concern to the physicians with whom they work in order to find solutions. For example, if physicians report that their time is overloaded with data entry, workflow could potentially be redesigned. Other members of the clinical team (e.g., nurses, pharmacists, physician assistants) as well as patients are drivers in EHR adoption and can identify workflow solutions. However, physicians' use of and attitude regarding EHRs are the most commonly studied among an overwhelmingly large number of publications (Junhua et al., 2013).

Successful adoption or modification of EHRs involves sociocultural change. Individuals' roles, workflows, decision making, and communication will change and adapt over time. Careful reconsideration and redesign is needed to align the changes and achieve the full benefit of the technology. Box 6-1 lists the identified principles for design, implementation, and policy for EHRs from Sinsky et al. (2014).

With the rapid adoption of EHRs in response to the Meaningful Use incentives, many health systems and practices have implemented the technology without pausing to work out these alignments. The fatigue of adapting to new systems is acknowledged by the committee. For example, of the 58,000 Medicare-eligible providers who attested to Meaningful Use in 2011, 16 percent did not re-attest in 2012. It is noteworthy, however, that 44 percent of the latter returned and attested in 2013 (HealthData.gov, 2014).

More than four out of five doctors say they prefer to continue working with this evolving technology that holds the promise of enhancing care rather than return to paper records (Friedber et al., 2013). Programs exist, such as the federally funded regional extension center program, to provide clinical teams with assistance in purchasing and implementing EHRs, training staff, and addressing how teams use EHRs in practice (Hsiao and Hing, 2012; Hsiao et al., 2014).

It is beyond this committee's charge to address the general challenges of EHR use. Other reports, such as the IOM report *Health IT and Patient Safety: Building Safer Systems for Better Care*, and the NRC report *Computational Technology for Effective Health Care: Immediate Steps and Strategic Directions*, better address these issues (IOM, 2012; NRC, 2009).

BOX 6-1
Principles of EHR Design, Implementation, and Policy

Patient-centered design

1. The use of an EHR should add value for the patient.
2. The primary function of an EHR is clinical care.

Health care professionals

3. The use of an EHR should improve, or at a minimum not reduce, the well-being of health care workers.
4. The use of an EHR should align the work with the training of the worker.
5. The EHR is a shared information platform for individual and population health.

Efficiency

6. The use of an EHR should minimize waste.
7. Electronic workflows should align with clinical work.
8. Various methods of communication, including nonelectronic forms, will be necessary for optimal patient care.

Regulation and payment

9. Sufficient resources should be available for the new work associated with the advanced use of an EHR.
10. Policies around EHR use should reflect the strength of the evidence base supporting them.
11. Regulatory balance between often competing values (e.g., clinical quality versus security or efficiency versus performance measurement) should be sought.

SOURCE: Sinsky et al., 2014.

However, the committee's awareness of these issues set the context in which decisions about adding additional data to the EHR were made. The committee was cognizant that its recommendations could increase the burden on health systems, clinicians, patients, and vendors, in addition to implementers of meaningful use regulations. As a result, the committee's criteria for selecting domains and measures for inclusion strove to provide a systematic approach to weighing the trade-offs (identified in Chapter 2).

COLLECTING SOCIAL AND BEHAVIORAL DATA TO INCLUDE IN EHRS

Data for EHRs can potentially be collected in many ways. It may be self-reported or reflect the judgment of a member of the clinical team. It may be imported through extraction from other data sources (e.g., vaccine registries or community datasets) or via a personal device. Even in low- and middle-income countries, data are now routinely collected via cell phones, personal digital assistants, and other modalities, and use in U.S. health care settings should be feasible (Glasgow et al., 2012). Data may be collected directly from the patient on paper or, preferably, via a computer, or through an interview with a member of the clinical team.

The most appropriate approach to collecting data varies among the social and behavioral identified measures. For example, while some EHRs use racial categories assigned by medical care personnel, the committee endorses capturing race by self-report as it is a cultural construct reflecting the individual's self-perception. A patient's residential address may be verified by administrative staff. Discussion of interpersonal violence may be most appropriate as part of the clinical interview. Social exposures can be inferred through geocoding of neighborhood indicators.

COLLECTING SELF-REPORTED DATA

Many of the measures of social and behavioral determinants of health identified by the committee are best obtained by self-report from patients or their caregivers. Estabrooks et al. (2012) detail strong support for using self-reported data elements on health behaviors and psychosocial factors for the EHR. Self-reported data are most reliable when the item contexts, stems, and response options are clearly written, reliable, valid, and meaningful to the respondent. If data are collected by self-report, the clinical team needs to take specific steps to ensure that the responses are complete and accurate from the patient's perspective. For example, for patients with low literacy or who are visually impaired, it may be necessary to have a staff member read and record the response to selected items. Language limitations also should be considered as well as use of alternative mechanisms. For example, audio assists using a patient's preferred language are currently in use in some settings. Box 6-2 provides an example of a clinic's success in capturing self-reported data to identify and treat at-risk behaviors.

Interviews during clinical encounters afford a measure of professional oversight but also add time and complexity to the encounter. The clinical team needs to decide whether the questions are best asked by the administrative staff, physician, nurse practitioner, physician's assistant, or another health professional. These individuals need to consider how to ask the question and how to communicate its importance to the patient. Cultural variations in terminology and meaning may reveal or obscure the exact meaning of the concepts and their role in an individual's life.

New electronic data collection software, Web-based data entry options, and EHR applications have made clinical implementation easier, allow-

BOX 6-2
At-Risk Behaviors, Identification, and Treatment in Clinics

In response to a concern regarding underdiagnosis of at-risk behaviors and outcomes, the University of Washington Madison HIV Metabolic Clinic developed a Web-based, self-administered patient-reported assessment tool and integrated it into routine primary care for adult HIV-infected patients (Crane et al., 2007; Fredericksen et al., 2012). The patient-reported assessment included brief, validated instruments measuring clinically relevant domains including depression, substance use, medication adherence, and HIV transmission risk behaviors. Patients complete the assessment just prior to seeing a member of the clinical team, and providers receive the results as they begin the patient visit. The assessment was integrated into routine HIV care with the support and coordination of clinic staff.

Workflow, technology, scheduling, and delivery of assessment results were completed using a plan-do-study-act (PDSA) cycle (Tufano et al., 2010). Researchers found the Web-based self-reported assessments to be a feasible tool that can be integrated into a busy multiprovider HIV primary care clinic. They assessed the impact of self-reported outcomes results on provider behavior and found that it led to increased provider awareness and action for at-risk behaviors and diagnoses (Fredericksen et al., 2011). Automated real-time notification of suicidal ideation was found to be particularly valued by providers (Lawrence et al., 2010).

Critical factors for successful integration of such assessments into clinical care include strong top-level support from clinic management, provider understanding of self-reported assessments as a valuable clinical tool, tailoring the assessment to meet patient and provider needs, communication among clinic staff to address flow issues, timeliness of delivery of results to providers, and sound technological resources.

The initiative was expanded into clinical care into seven HIV clinics as part of the Centers for AIDS Research Network of Integrated Clinical Systems (CNICS) cohort. With the addition of each clinic, a tailored integration was developed to meet that clinic's needs particularly related to clinic flow and provider feedback and differences in electronic health records. As part of CNICS, HIV-infected patients across the United States have completed the assessment approximately 34,000 times providing a wealth of clinically relevant data to improve clinical care, and population health, and to facilitate clinical research (Crane, 2014).

ing for immediate scoring that can be displayed for review during clinical encounters. Clinicians and patients prefer electronic collection (Valderas et al., 2008), which is associated with lower rates of unanswered questions than with paper forms and higher rates of reporting risks such as violence in the home and substance abuse (Gottlieb et al., in review). Reproducibility of electronic data collection is high, reducing missing data and allow-

BOX 6-3
Priority Considerations for Using Self-Reported Data

1. Specifying the goals for data collection (screening, diagnostic, outcome assessment)
2. Selecting the patients, setting, and timing of assessments
3. Determining which questions to administer
4. Choosing a mode for administering and scoring the questionnaire
5. Designing processes for reporting results
6. Identifying aids to facilitate score interpretation
7. Developing clinical strategies for responding to issues identified by the questionnaires
8. Evaluating the impact of the patient-reported outcomes intervention on the practice

SOURCE: Adapted from Snyder et al., 2012.

ing complex skip patterns. Patients interacting with modern systems can experience a consistent look and feel across content and selection methods. Internet connectivity is rising in both private and public clinical locations. Approximately 80 percent of American households indicate regular Internet use (ESA and NTIA, 2011). This rise in connectivity has increased the range of locations where patients can complete questionnaires (e.g., at home, on waiting room kiosks, or on a personal smartphone).

Beyond the time required for data acquisition, it also takes time to interpret and develop appropriate clinical responses to issues identified from the data. The clinical team needs to consider the time during the course of an encounter that is most appropriate to collect or review the information. Some clinics start patient appointments 20 to 30 minutes in advance of the physician encounter to provide enough time for completion of self-reported data before the physician visit begins. If data are collected at home via a patient portal, personal health record, or an email link to a Web-based survey, they may need to be obtained close in time to an encounter so responses are relevant when physicians review the results. Whatever the sequence, time has to be set aside for these steps. It is also important for health care systems to help patients understand the purpose and the value of the information being collected by self-report, when that method is used (Greenhalgh et al., 2005; Lohr and Zebrack, 2009).

Acquiring social and behavioral data at the point of care may generate the expectation that the clinician will, in turn, act on that information.

Indeed, best practices for acquiring information about some social and behavioral data require that an intervention plan be in place (Ockene et al., 2007). This is especially true for problems that fall within the traditional health care system, such as depression. Otherwise, the patient may be left with a positive clinical finding, but not the tools needed to address the health need. Even if it is not possible to address some domains within a primary care setting, efficient and effective intervention resources often exist through referrals. Shared decision-making aids may be indicated that would use data to help patients and their health care teams collaborate to make informed decisions (Glasgow et al., 2012). The International Society for Quality of Life Research's 2012 guide for implementing a self-reported data collection system in clinical settings identified eight key design considerations for self-reported data collection systems, as seen in Box 6-3.

STORAGE OF SOCIAL AND BEHAVIORAL DATA IN EHRS

Using the EHR as a repository for social and behavioral domains is challenging. EHRs originated as the legal record of medical encounters and admissions. Thus, beyond their role in informing diagnosis and treatment, EHRs are legal institutional archives of care events organized at the level of the individual. The data stored in the EHR still largely reflect the care experience and rarely present a complete view of the patient's health state. Elements of the EHR that document patient history and progress notes may be unstructured narrative or structured as text insertions into structured forms or numeric data. While rich narrative may be the best way to tell parts of the patient story or a clinician's assessment of medical information and its meaning, structured data and standardized measurement are needed to enhance retrieval, analysis, and interoperability to support clinical care, population management, and clinical research (Fridsma, 2013).

The committee's criteria for selecting a domain include availability of a standard measure. Several projects are facilitating standard representation of behavioral data, including the Grid-Enabled Measures (GEM) database (Min et al., 2014); consensus measures for Phenotypes and eXposures (PhenX) (NIH, 2012); the Patient Reported Outcomes Measurement Information System (PROMIS) (PROMIS Network, no date); the NIH toolbox (NIH, 2006–2012); and the National Collaborative on Childhood Obesity Research, which have developed standard measures and common definitions (NCCOR, 2014). The committee strove in Chapter 4 to provide as much guidance as possible in order to support consistent acquisition of social and behavioral data according to an interoperable standard. Chapter 4 identifies common metrics, where available, and standard measures for use in EHRs.

Interoperable standards are needed for health information exchanges

(HIEs) to succeed. HIEs commence when one health care professional or health system shares data electronically with another. Reducing the burden of phoning, printing, scanning, and faxing potential sensitive documents will improve the quality, safety, and efficiency of health care delivery (HealthData.gov, 2014). Once information is stored in an EHR it is subject to federal and state laws and regulations and to institutional policies and procedures, which may place significant barriers on the efficient reuse of the data outside the point in which the data are captured. Appendix B provides a more robust description of privacy protection issues.

As described earlier, select elements for some determinants of health may be found in other sources related to the patient, such as EHRs from other institutions; personal health records, third-party data integrators, such health risk appraisals gathered by insurers or employers or clinical data registries, community agency datasets, national surveys, and datasets from other sectors like retail. Presently there are few straightforward ways to transfer data from external data sources to EHRs or vice versa. Importing data from external sources requires the importing institution to determine the provenance of the data, its accuracy, and its validity. An additional challenge in this area arises from the absence of data standards and terminologies that ensure the meaning and interpretation of the data remain true to their original source.

Open architecture models of health information systems, such as that advocated in the report by JASON/MITRE Corporation *A Robust Health Data Infrastructure* (AHRQ, 2014), hold the best promise for ensuring the data flows needed to make social and behavioral determinants of health are accessible to the patient, in clinical care encounter, to the health system, and to society. This document lays out a health information infrastructure that represents a significant departure from the one(s) existing today. Today's health information infrastructure can best be described as a series of hub-and-spoke configurations, where the hub represents an institution's EHR system and each spoke represents a one-to-one pathway to an authorized business partner where the business partners may be another health care delivery organization, a health information exchange operation, a clinical laboratory, or a physician's office. Sharing data devolves to a process of opening a trusted channel of information flow and creating a point-to-point connection. Fine-grained access control and data exchange are nearly impossible, as records are exchanged in totality, not as individual data elements.

In the robust data infrastructure envisioned in the JASON report, data are stored at the point of acquisition and integrated at the point of need. Record systems are separated from the tools that operate on them, and information integration is driven by clinical or policy need, not by acquisition strategies. With such an open architecture, the committee's recommended data elements could be acquired from a wide variety of sources. Integration and updating at the point of care would be feasible but not restricted by the constraint of the clinical information systems.

Several EHR vendors are beginning to collaborate in order to achieve interoperability of records (Bresnick, 2013; Moukheiber, 2014; ONC, 2012). These are important steps and offer the possibility that priority health-relevant social and behavioral domains collected in a clinical encounter at one institution could be available to clinicians at a different institution.

PRIVACY PROTECTION ISSUES

Risks to the patient in some sensitive areas such as substance use or violence represent considerable challenges to collecting data. A recent pilot project examining interstate behavioral health data exchange demonstrated that some privacy concerns need to be addressed to facilitate exchange of sensitive behavioral data nationwide (Parker et al., 2014). However, basic safety measures are widely used. Covered entities (e.g., providers, health systems) and their business associates need to be in compliance with the Health Insurance Portability and Accountability Act of 1996 (HIPAA). HIPAA's Privacy Rule[1] establishes the rules governing the use and disclosure of identifiable health information in either paper or electronic format. HIPAA's Security Rule[2] establishes the security safeguards to be adopted to protect electronic identifiable health information. Other laws govern public health authorities, and state laws are also applicable (see Appendix B for a commissioned paper on privacy concerns). When possible, data can be de-identified to better protect anonymity. For example, in syndromic surveillance, the public health entity only needs to know how many cases there are and, perhaps, associated information such as age, sex, neighborhood, but it need not know the specific names of individuals. In cases where there is a need to individually link EHRs to a public health registry, the data cannot be de-identified, thus raising privacy concerns. However, the data that are transmitted can be encrypted.

Institutions should inform patients about the specifics of data sharing. For example, if data are being shared with public health officials, patients should not only be informed that this is occurring; they should be informed about the rationale and benefits of that information being shared as well. Further protections include asking persons who handle confidential data to sign oaths of confidentiality with clear penalties spelled out for unauthorized release of protected information and making sure that all information

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[1] 45 CFR Part 160 and Subparts A and E of Part 164.

[2] 45 CFR Part 160 and Subparts A and C of Part 164.

is password protected within the system. Audits of attempts to access the data can be conducted to assure that only those who have a legitimate purpose in looking at the data can do so.

With the above protections in place, routine collection of these types of potentially sensitive data may not only provide important information for diagnoses and treatment but may have the additional benefit of normalizing or destigmatizing discussion of sensitive issues in clinical practice.

RESOURCE CONSIDERATIONS

The business model for capturing social and behavioral domains and measures into the EHR has yet to be fully realized because few examples exist. If care is planned mindful of the patient's social and behavioral profile, the cost savings from social and behavioral interventions could be substantial as described in earlier chapters. However, those who bear the costs of collecting and acting on social and behavioral determinants of health may not be the ones who benefit from the cost savings. These benefits accrue to society, health care payers, and health systems that are reimbursed for population management. While some of these benefits are near term, many accrue over a period of years. The costs of adding social and behavioral domains to EHRs, such as programming, modifying workflows, and intervening on positive screens, often fall on the clinical practice or hospital. The movement toward population management and accountable care organizations may address this misalignment over time. In the meantime, misaligned costs and benefits remain a barrier.

Costs and benefits are not just financial, and they will be experienced differently depending on the clinical practice. A common question is the time needed to capture the measures or manage the self-reported information. In addition, time and resources will be needed to address the risks identified. Some care settings may be better equipped than others to meet these needs. Large health systems are more likely to have access to specialized programs such as stress management or smoking cessation than small practices. However, addressing these determinants is an important aspect of quality care which is equally relevant for all practices, small and large. Over time, the movement toward patient-centered medical homes, population health management, and health care data exchange will reduce these differential burdens. In the meantime, the committee's recommendation of a parsimonious set with the fewest measures that would provide a balanced psychosocial vital sign minimizes the burden.

Four key stakeholder groups are likely to be affected by the inclusion of social and behavioral determinants of health in the EHRs: individual patients, clinicians, health care providing institutions, and society in general. Each of these groups stands to benefit in unique but interconnected

TABLE 6-1 Stakeholder Concerns and Examples of Mitigation Strategies for EHRs

Stakeholder	Concerns	Mitigation Strategies
Patient	• Why is my clinician asking about my education, drinking behavior, financial resources, and so forth? • Will this be asked at every encounter? • How will this information be used? • Who will be able to see my answers? • How are my answers protected?	Mitigation depends on public education and clinician attitude and explanation, for example: • Asking every patient in a manner that is aligned with the patient's preferred language and cultural affiliation, and is respectful of the sensitive nature of the content. • Telling patients how you will use the information to help them (e.g., personal prescription, as referenced in Appendix B). • Preparing patients in advance—no surprises.
Clinical team	• Who should ask each of the questions? • What is the best way to state the question? • How do I change my workflow to accommodate this new material? • What do I do with the answer(s)? • How do I make sure there are ways to follow up on needs that are uncovered?	Mitigation involves adaptation of workflow and clinical strategies, including • Using dashboards to track use and impact. • Determining as a team where information gets stored and recorded. • Acquiring basic or continuing education to devise clinical interventions informed by this information.
Health care system	• What is our institution's responsibility to record, store, and use this information? • Who should capture it? • How do we build an accountability model to make sure our staff is ready to assess, acquire, and use this information? • What is our institutional liability for acting on this information? • How do we determine the return on investment?	Mitigation involves a population management strategy, including • Communicating executive commitment. • Assigning priority and resources. • Starting small and building on what is there. • Obtaining post-implementation feedback. • Establishing two-way consented connections to community resources. • Resourcing intervention teams. • Forecasting and tracking return on investment.

continued

TABLE 6-1 Continued

Stakeholder	Concerns	Mitigation Strategies
Society	• Are these the right, best, and most parsimonious set of social and behavioral determinants of health? • How can we trust that our health care systems will use this information properly? • How do we prevent misuse? • How can communities benefit from appropriate use of this information about our populations?	Mitigation involves community health assessment and improvement at local and national levels, including • Using social and behavioral determinants of health in the EHR for community planning, interventions, and evaluation. • Determining the roles of voluntary bodies, accrediting agencies, and public health in ensuring safe and appropriate use. • Developing community agency policies. • Developing public policies and regulations that allow clinicians to act on self-reported data and protect them from liability for undetected reports.

ways, and each is also likely to have unique concerns which can be mitigated by careful attention to implementation strategies. Table 6-1 outlines implementation questions from various stakeholder perspectives and examples of mitigation strategies discussed by the committee.

LINKING DATA FROM EHRS TO PUBLIC HEALTH DEPARTMENTS AND COMMUNITY AGENCIES

Linking data from EHRs to local public health departments and community agencies provides several advantages to patients, providers, and the broader community. Information can flow in both directions. For example, data in EHRs can enable public health practitioners to identify groups of persons affected by environmental pollutants and identify areas that may need environmental mitigations. Clinicians can use geocoded environmental data to coach individual patients on risk mitigation or to tailor treatment. Reports of symptom constellations can help public health authorities to recognize potential epidemics or toxic exposures much earlier than in the past. Conversely, local immunization registries can be used to feed immunization history records to all local EHRs to know about vaccinations, and other registries can be created to identify medication adherence or interpersonal violence reports.

Public health departments or community agencies are often in the best position to address certain problems, such as food insecurity, lack of housing, and social isolation. The manners in which social and behavioral domains may be addressed fall far outside the typical interventions found in health care. For example, food insecurity may be alleviated by access to government-funded food assistance programs, but patients may need help in navigating the enrollment process. Individuals may benefit from health interventions such as group visits, but some may also need community-level interventions. Box 6-4 describes a promising initiative by an organization to address basic resource needs.

Data in the EHR can also help public health departments to assess the success of community interventions in areas such as increasing physical activity, improving diet, and substance use issues. A better understanding of the smoking prevalence, exercise levels, and dietary habits in a community would enhance development of interventions to decrease community-level cardiovascular disease. This additional data may also help in understanding transmission of communicable diseases. For example, diseases spread by air droplets (e.g., tuberculosis) are more likely to be transmitted in areas where people are living closely together. As mentioned in earlier chapters, public health agencies can use geocodable data to create neighborhood and community health information maps that overlay information on health outcomes (e.g., obesity, diabetes, cardiovascular disease) with neighborhood characteristics (e.g., walkability, food index scores, poverty level).

BOX 6-4
Health Leads Connections to Community Resources

Innovative groups like Health Leads, headquartered in Boston, Massachusetts, work to enable clinical health teams to "prescribe" basic resources like food and heat just as they do medication. They recruit and train college students to "fill" these prescriptions by working with patients to connect them with the basic resources they lack. Health Leads receive referrals by clinical teams, which are also recorded in the patient's EHR. By completing a full intake with patients to see what their needs are, they are able to work with resources in the community to address those needs. In the case of food insecurity, Health Leads may direct a patient in need of provisions to a food pantry and will follow up to see if the patient went and received food. If not, they will seek out additional resources until the patient's needs are met.

SOURCE: Tirozzi, 2014.

BOX 6-5
Using of Geocoding for Supporting Public Health Surveillance of Social and Behavioral Determinants of Health

The Denver Public Health Department is working on a project called the Colorado Health Observation Regional Data Service (CHORDS), with a goal to support public health surveillance and engage with communities. Using CHORDS, they are able to extract body mass index (BMI) data from electronic health records (EHRs) from various partners, using minimal data to protect patient privacy. This information is then geocoded—including the demographic data with the exact location, which can then be linked to census tract such as income and other social and environmental data. The data allow the Denver Public Health Department to superimpose factors such as walkability, availability of food, restaurants, green space, and poverty on top of the BMI information from EHRs. This information can be used to create specific maps, such as percentage of child obesity. Creating this registry allows communities to examine the health issues in their own neighborhoods and gives the public health community insight into population health.

The Denver Public Health Department also hopes to implement personal prescriptions using community resources. An example of this would be to create a walking map for an individual in their own neighborhood, highlighting the route as well as the health effects such as calories burned. This resource can also use facilities within the community, such as alerting community members to exercise classes near their home.

SOURCE: Davidson, 2014.

This information can be linked back to the health care systems and clinical teams informing them of how well or how poorly the populations they are serving are doing. Box 6-5 details the Denver Public Health Department's use of geocoding from the EHRs to engage communities.

Patients need to understand the role of public health agencies and the links that the agencies have to one's clinical team. Patients are not fully aware of the responsibilities of local health departments and may be surprised to discover that their clinical information (e.g., notification of a communicable disease) has been shared with the health department. They might feel that their doctor has compromised the confidentiality of their health record if they receive a call from the health department asking them about their history of a contagious disease, such as a specific food-borne illness. These risks can be mitigated by ensuring that patients are notified about shared data and the roles that health departments play in safeguarding community health. While data regarding domains in this report are more likely to be used in the aggregate, there may be concerns about the sharing of and use of this information.

ANTICIPATING AND PREVENTING UNINTENDED CONSEQUENCES

In some instances, the introduction of the EHR has led to unintended consequences (Ash et al., 2004), including increases in medication errors and data entry failures. Adding social and behavioral domains to the EHR may aggravate existing unintended consequences as well as create new ones. As described earlier, most data (but not all) will be provided by patient self-report, but there will be a need to provide assistance or accommodate patient preferences in doing such. There will also be a change in the clinical workflow that requires the clinical team to verify and interpret rather than simply acquire information. Additionally, the inclusion of new screening tools may inadvertently lead clinicians to minimize or skip previously well-established parts of the clinical evaluation. For example, the use of a three-question screen of alcohol abuse might deter a clinician from undertaking a complete alcohol history. As with any change in clinical information flow, careful planning can mitigate some unintended consequences, and constant surveillance and evaluation are needed to detect those that were not anticipated.

The ultimate value of incorporating the social and behavioral domains of health in the EHR lies in engaging the patient and aligning health service and care. Such redesign is a long-term answer to facing and addressing the implementation challenges summarized in this chapter. The barriers and suggested interventions highlighted are intended to act as a reference to guide stakeholders along this journey.

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7

Looking Toward the Future

As noted in the introduction, a variety of forces are aligning to create a demand for social and behavioral information in electronic health records (EHRs). These forces include the growing accumulation of evidence that social and behavioral factors play a major role in the onset and course of disease, morbidity, and mortality (McGinnis and Foege, 1993; Woolf and Braveman, 2011; Woolf et al., 2007); concerns about the costs of health care and its effects on the U.S. economy (IOM, 2012; KFF, 2012); and current and anticipated health care costs associated with the treatment of chronic conditions, such as diabetes (KFF, 2012; Thorpe et al., 2004, 2010).

There are several indications of growing interest in addressing social and behavioral determinants of health and including relevant data in EHRs. In turn, individual health systems are modifying their own EHRs to incorporate such information. Innovative programs are screening for social hardships of patients in order to provide services to address these needs as part of the clinic visit (e.g., organizations such as Health Leads, described in Chapter 6, and medical–legal partnerships). Importantly, the Office of the National Coordinator for Health Information Technology (ONC) has expressed interest in considering the inclusion of more social and behavioral domains in the EHR as a possible Stage 3 Meaningful Use requirement. All of these efforts will be facilitated by a standard set of measures to assess the most relevant domains.

The measures that merit inclusion in all EHRs (as well as which are appropriate for specific populations) are those that will enable more effective treatment of individual patients in health care settings; more effective population management for health care systems and for public health agencies; and discovering the pathways that link social and behavioral factors to biological functioning, disease processes, and mortality that may inform new treatments and interventions. For this to occur, data should be accurate and useful to patients, the clinical team, systems, and researchers. Thus, in making its judgments about what to recommend for inclusion in EHRs, the committee leaned heavily on the current evidence of the link between each domain and health outcomes; the availability of a standard reliable and valid measure of the domain; the clinical usefulness of the measure; the feasibility; and the lack of sensitive information, causing patient discomfort of capturing the measure in the clinical workflow.

The committee recognizes that criteria used to evaluate measures of domains may vary in their nature and emphasis depending on the purpose for which they are being used. There is rarely a true "gold standard" for evaluating whether a given measure of a social and behavioral determinant is fully and accurately capturing the intended concept. Psychometric testing can provide evidence of aspects such as internal consistency, stability over time, convergent and discriminant validity, and the extent to which the items cover the full range of the construct. Meeting these criteria often necessitates multiple items, creating a trade-off between validity of the measure and its ease of administration. A longer, well-validated instrument may become the gold standard against which shorter instruments are tested.

Many of the measures the committee reviewed were not developed for use in clinical settings but for research on a conceptual domain in relation to health—and to other aspects of life. Researchers often develop variants of methods and measures to capture the conceptual domain in relation to the specific outcome they are studying. Finding that multiple measures of the same concept show significant associations with a single outcome or related outcomes provides evidence of the "robustness" of the association. Ironically, however, that benefit conflicts with the need for a standard assessment.

The question of clinical use of these measures is relatively new. While all of the measures the committee evaluated have strong links to health, the findings frequently emerged out of population-based surveys with self-reported health outcomes. There is a much smaller evidence base of the implications for clinical care, or of the effectiveness of actions, or interventions to modify the underlying state or to modify treatments by taking into account the patient's social context and psychosocial risks. This is an important emerging area of research.

MEASURES IN NEED OF DEVELOPMENT AND MORE RESEARCH

The committee's findings and recommendations necessarily reflect the *current* status of knowledge about the social and behavioral determinants of health and of the measures of the identified domains of health determinants. The initial choice of 17 candidate domains to be considered for inclusion in EHRs out of a set of more than 70 potential domains was based on the strength of the evidence of the association of each domain with health and the usefulness of that information. In the coming years, new research may point to the importance and usefulness of domains that were not selected based on current knowledge. Final decisions about which measures meet the criteria for inclusion in EHRs reflect not only the current state of knowledge but also considerations regarding their feasibility and priority for inclusion in an initial parsimonious set of social and behavioral measures for EHRs. Some measures in Figure 5-1 are equally ready to be deployed in EHRs as are those in the recommended set, but they received lower priority in terms of usefulness. As shown in Figure 5-1, other measures are very promising and potentially important, but fell short on aspects of readiness for inclusion in all EHRs. The domains and measures that were not included in the recommended panel merit greater attention as valuable targets of research. The committee notes below some of the current shortcomings—with measures, metrics, intellectual property rights, and self-reported data—and some activities that are under way to address these gaps. As these deficits are overcome, the resulting measures should be considered for addition.

Measures in Need of Development

Several domains showed a strong association to health and would be useful, but the committee could not identify adequate measures or related interventions for them. Many of the measures identified in Figure 5-1 that the committee did not recommend for inclusion in EHR are measures that would benefit from further development. Once suitable and standard measures are developed, these domains and their measures can be considered for inclusion in EHRs. The committee noted two examples of measures that would benefit from further development for EHR inclusion and are not mentioned in Figure 5-1: exposure to violence (broadly), and occupation. Violence includes a wide range of abusive behaviors and affects men, women, and children as victims and perpetrators. Although violence is an important domain related to health, the committee identified a research gap in the development and validation of measurement tools. For example, in reviewing the evidence related to violence against elders, the U.S. Preventive Services Task Force (USPSTF) found insufficient evidence to recommend routine assessment of elders for exposure to violence because of the uncertainty of the benefits and harms of doing so (USPSTF, 2013). Children are also a vulnerable population in relation to abuse, but despite great interest and concern about children's exposure to violence, validated measurement tools are lacking. Child abuse is often visually identified by the clinical team or outside of the health care setting, and legal systems are in place to protect the child. The existence of reporting requirements adds complexity to obtaining measures of children's exposure to violence.

Interpersonal violence measures are an unmet need. Better evidence is available on intimate partner violence. A systematic evidence review by Nelson et al. (2004) for the USPSTF revealed that more women than men experience intimate partner violence, and most studies about screening and interventions for intimate partner violence enroll only adult women. The task force viewed screening for intimate partner violence for women of reproductive age as having moderate net benefit. The committee noted the need for more research regarding screening measures for violence for other populations, as well as the need to identify a common metric for interpersonal violence.

The second example of an important domain that is not yet feasible for inclusion in EHRs is occupation. Occupation has a number of characteristics, including employment status (e.g., working full-time, working part time, unemployed), as well as type of employment and conditions associated with the work environment (e.g., demanding physical labor, clerical work, caring for others) and prestige (e.g., unskilled labor, professional). Research has identified risks for health outcomes associated to specific jobs and informed the development of preventive measures to reduce or eliminate exposures (Sabatini et al., 2012; Ziegler et al., 2002).

Reflecting the importance of occupation to health, a number of organizations, including the American Public Health Association, the Council of State and Territorial Epidemiologists, and the American College of Occupational and Environmental Medicine, have published statements calling for the inclusion of industry and occupation in EHRs. A 2011 letter report from the Institute of Medicine observed that "occupational information could contribute to fully realizing the meaningful use of EHRs in improving individual and population health care" (IOM, 2011, p. 42). The committee agreed with the sense of the statements asserting the importance of occupation in relation to health. It not only impacts health directly, but knowledge of the characteristics and demands of their patients' work may be relevant to clinicians in making treatment choices.

Despite its importance, the currently available measures of occupation are lengthy and complicated to code. As a result, occupation was not included in the recommended panel.

These shortcomings may be rectified in the future. The National Institute for Occupational Safety and Health (NIOSH) is currently developing and standardizing specific measures that capture a patient's industry and occupation, including measures on work schedule, employment status, and external causes related to injury and poisoning (i.e., ICD-10 codes)

(NIOSH, 2014). Currently this coding for occupation is too time intensive to be practical for use in an EHR, but if this hurdle can be overcome, it could be added at a later time.

Intellectual Property Limitations

Some domains currently have adequate measures, but they are not freely available because of copyright protections, and they either require purchase or the measures are available only to researchers. For example, patient activation has been shown to play an important role in enabling greater patient involvement in decision making and better clinical outcomes. However, the leading measure, PAM, is proprietary and does not meet the criterion of being freely available for use in EHRs. The need for a more widely accessible instrument has been recognized in the field, and several researchers and groups are working on alternate measures. These have not yet been fully validated but should become available within the next few years.

Lack of a Common Metric

Other domains had measures that met the criteria for inclusion in EHRs but had no agreed-upon common metric. Health literacy, stress, and food insecurity are all examples. A common metric is desirable because it provides greater comparability over time, sites, and populations; facilitating continuity over time. By relating measures of a domain to a common metric, if specific measures change and new ones develop, the common metric remains. For example, rapid advances are occurring in the development of personal devices and sensors to measure physical activity. However, regardless of the instrument used to measure physical activity, the measure can be converted into a common actionable metric (e.g., minutes of moderate or vigorous physical activity per week).

Although the existence of a common metric is desirable, its absence was not sufficient to remove a domain and its measures from committee consideration. Because several measures were included for domains lacking a common metric, future work is needed on developing such metrics.

Self-Reported Data

Most of the recommended measures rely on self-report, which can be subject to error and bias. Technological advances may allow collection of more objective indicators and information on experiences that individuals may not be able to remember and report reliably. For example, rather than relying solely on a self-reported measure of sleep duration or quality, personal devices now exist that monitor levels of sleep behavior. Sensors that record data for review and upload to the EHR if appropriate—while not without their own limitations—may eliminate or reduce the need for having to ask individuals about their behavior.

IMPLICATIONS OF INCLUDING SOCIAL AND BEHAVIORAL INFORMATION IN EHRS TO STAKEHOLDERS

The use of EHRs is expanding at an increasing pace, and the data that are collected and stored in such records have the potential to improve clinical practice, population health management, and health research, but they may also pose challenges. As a result, the committee considered potential implications for a number of potential stakeholders if its recommendations are implemented. The implications encompass both opportunities for new or more effective actions as well as potential demands and challenges. Some of these are discussed below and summarized in Table 7-1 at the end of this section.

Office of the National Coordinator for Health Information Technology

The ONC, through its Health Information Technology for Economic and Clinical Health Act (HITECH) program, has already made some inroads in collecting social and behavioral determinants of health that are of high clinical priority (e.g., tobacco use). The deliberations and conclusions of the committee can inform new standards for data domains that have before this time received little attention.

The core panel of measures recommended by the committee pulls in aspects that should have an important and broad effect on the need for services, the delivery of health care, and the interaction with the health care team (including electronic communication). The committee has based its recommendations on factors important to ONC, including concrete evidence about the clinical importance of each determinant, availability of standard measures of the determinant, and the expected amount of work necessary to collect the determinant. The recommendations should provide helpful guidance for further development of Meaningful Use regulations. As HITECH shifts its emphasis to improving outcomes, the social and behavioral determinants of health will be critical to selecting the right path for each patient and to making sure that benefits accrue equitably across the nation's population.

The committee recognizes that adding anything to the HITECH program has costs and consequences. The determinants are not static; there will need to be ongoing review and maintenance of the current core set and potential additions in the future. Monitoring the process and outcomes of implementing the addition of social and behavioral domains to EHRs and reviewing the emerging literature for new measures and domains that should be added later on will take time and resources. These demands should be viewed in the context of the potential for the addition of the committee's core set of determinants to allow the nation to move forward in a more consistent and fair manner.

Research Sponsors

Research sponsors will have new opportunities to expand and enrich their research portfolios by supporting research using the data provided by the recommended panel. These measures assess the key determinants of health and provide new types of data in a standard form that can enable novel research. The addition of social and behavioral data would not only spur the development of new studies on social and behavioral determinants of health and of the effectiveness of health care; they can also be used in conjunction with data on genomics being linked to EHRs. The recommendations may also be useful to research sponsors working to support development and use of national data networks by informing data standards.

The flip side of these new opportunities for cutting-edge research using these determinants in EHRs is that there will be more demand for research dollars to support this work. In addition, growing awareness of the importance of having validated measures of multiple domains should also increase the need to support basic research on social and behavioral processes and how they can be modified. This work is likely to be interdisciplinary and require collaboration both among units within funding groups (e.g., across the National Institutes of Health [NIH]) and across funders (e.g., NIH, Agency for Healthcare Research and Quality [AHRQ], Patient-Centered Outcomes Research Institute [PCORI]).

The NIH has a particularly important role as the largest funder of health research. The Office of the Director of the NIH produces strategies and plans for advancing research across all of its institutes and centers. The committee sees an opportunity for better identification and use of social and behavioral determinants of health collected in EHR through the development of such a plan for this field. The Office of Behavioral and Social Science Research (OBSSR) could be the driving center, ensuring input across the many NIH institutes and centers. OBSSR could also be the visionary, informing data standards for the national data networks in the field of social and behavioral determinants of health. With the availability of new types of data collected, novel avenues for research will arise. While funding streams will need to be identified, the research garnered will likely hold tremendous benefits.

Quality Improvement Organizations

Organizations such as AHRQ, the National Quality Forum, the National Committee for Quality Assurance, and the Joint Commission will benefit from access to additional information that can enable them to better monitor the progress of health care providers and systems in providing care that improves patient outcomes and reduces disparities. The added measures provide relevant information on patient outcomes and provide greater explanations of contributors to disparities in access to care (e.g., how education or financial resource strain alters access to or use of health services). Having access to these data may also provide additional parameters upon which to make risk adjustments.

Three challenges arise from the inclusion of these determinants of health into the quality assessment process. First, the development of clear EHR specifications for social and behavioral quality-related measures and subsequently obtaining those measures will add burdens both to the standards organizations and to already overburdened institutional information technology services. Second, inclusion will require expanding notions of what constitutes quality and how more enduring characteristics of the individual and elements exogenous to the health care system can, could, and should be incorporated into the quality assessment process. Finally, there may be challenges to incorporating social and behavioral indicators as quality indicators if these are believed by the clinical care professionals and systems to be immutable or considered out of scope of their purview. The emergence of the concept of the accountable care organization (ACO) is laying the groundwork for broader consideration of quality; however, this shift has challenges of its own and may take several years to achieve fulfillment.

The Center for Medicare & Medicaid Innovation

The recommended measures will provide options for the Center for Medicare & Medicaid Innovation (CMMI) to expanded practice-based data and use more comprehensive information about patients and populations, especially in those areas most likely to create challenges in implementation. Social and behavioral determinants of health affect what care is needed, how to best deliver it, and how to measure success. CMMI programs can benefit from the information both at the population level—for example, to understand regional differences in uptake for different CMMI models—and at the individual level—for example, to tailor optimal treatment to the patient. This will, however, require an explicit effort to include the social and behavioral determinants of health into the CMMI programs, including demonstrating projects and evaluation.

EHR Vendors and Product Developers

EHR vendors and product developers are currently responding to Meaningful Use objectives with the goal of achieving interoperability between their products. The current report should help inform those activities, especially if ONC, the Centers for Medicare & Medicaid Services, and providers embrace this report's recommendations. The emphasis on standard measures will facilitate definitions of specific fields that product developers and vendors need to create to implement the addition of social and behavioral domains when such data are desired. The committee's recommendations provide guidance on a standard set of domains and measures that may be useful in designing population health product offerings. These offerings will require patient self-report data capture capabilities that coordinate with clinical workflows and support new ways of analyzing and visualizing social and behavioral data to aid in clinical decisions and provider population health goals. New EHR functionality will also be needed to geocode patient addresses and link to external data sources.

Health Care Systems and Accountable Care Organizations

Health care systems and ACOs are generally charged with providing care and services for individuals and populations of individuals who enroll for care from their organizations. Currently, ACOs and health care systems maintain few standard data on social and behavioral determinants of health to help with their overall management of those they serve. The recommended set of social and behavioral domain measures will provide standard data for managing individual and population health and better risk adjustment for quality assessment and payment adjustment. Additionally, under the community benefit provisions in the Patient Protection and Affordable Care Act,[1] nonprofit hospitals are required to conduct needs assessments and to document the benefit they have provided to their community. Having more robust social and behavioral determinants of health in their EHRs may contribute to each hospital's assessment, in turn aiding their ability to allocate their resources to address identified needs.

Some domain measures that were not included in the parsimonious panel recommended for inclusion in all EHRs could provide additional useful information. They should be evaluated by these organizations depending on the populations they serve and the types of services they are providing (e.g., sexual identity). The collection and analysis of such measures could inform modifications and later decisions about inclusion in a wider array of EHRs.

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[1] Public Law 111-148.

Health care systems and ACOs will arguably have the greatest burden as a result of these recommendations. Challenges on small practices will likely be greater than on larger health care systems. In addition to changing their clinical information systems to capture, store, and report data, they will have to adjust their workflow to collect and act on the new data. As detailed in Chapter 6, every time a new domain is added to the EHR, systems and workflows need to change to adequately capture the data elements. Moreover, availability of data on these domains will identify areas of need. Systems that are responsible for all the care needs and are paid on a capitated or total population system (not fee for service) may be most motivated to address these needs because doing so may reduce demand for other services. Some programs have demonstrated the usefulness of targeted approaches, but most of these have never been taken to scale. This represents a challenge that all ACOs and systems will need to face.

Health Professionals

Clinical care providers and teams and administrative staff will have access to a more comprehensive picture of the patient state. Standard collection of social and behavioral domain measures along with interoperability of records could allow for different health providers to screen and access patient data and eliminate the need for burdening the patient and clinical team with redundant questions and entry of data. Access to such information could enable providers to engage more effectively with patients in shared decision making with the clinical team about treatment options, prevention, and care. As with health systems, providers will need to adjust their workflow to collect data on social and behavioral determinants of health and modify their clinical information technology systems accordingly to incorporate collection, review, and action on the data. Health professionals will likely need additional education about social and behavioral factors and interventions. Interprofessional education and other training opportunities to create links between public health, medical, nursing, and other health professional education will likely aid efforts to advance the collection and use of social and behavioral information.

The committee recognizes that effective population health management adds burden in the short term to the health system, especially to smaller practices. However, in the long term, the result will be improved patient and population health outcomes. Recognizing this, the committee recommended a parsimonious panel of domains with standard measures hoping to minimize this barrier to adoption.

Patients and Patient Advocacy Groups

Patients and their advocates will have access to new tools to help assure better care and outcomes. The committee's recommended measures were selected as patient-centered tools and are outcome oriented whenever possible. Advances in health care require that individuals participate knowledgeably and actively in their own health care to realize the full benefit of shared decision making. Inclusion of standard data and language about social and behavioral determinants of health should help patients avoid redundant reporting and achieve more effective patient-centered care. At the same time, some of the social and behavioral questions may deal with sensitive or uncomfortable issues, and patients and advocates may have privacy concerns. Some may not understand the links between social and behavioral states and their health. Community and patient education efforts will be needed to address these concerns and prepare individuals to participate in shared decision making and interventions. Patients and patient advocacy groups should be active participants in ensuring that privacy protections are in place—particularly when data that are considered sensitive are involved.

Public Health Agencies

Public health agencies have long understood the connection between social and behavioral determinants of health and the health of communities. However, there has been limited data capture of social determinants on an individual level or links with documented health outcomes. Having these determinants routinely collected as part of the EHR will enable communities to better understand how these determinants are affecting health and to develop community-wide interventions to improve population health.

Greater use of electronic health care data by public health agencies could enable better coordination of efforts and help break down the artificial walls between public health practice and clinical care. Public health programs may also be especially well qualified to address privacy concerns. They can inform the broader public about social and behavioral determinants of health and how the information on their characteristics will be used in both clinical and public health practice. While some data can be de-identified, it will be necessary for people to understand when their medical data will be used in a way that identifies them and when it will be used in ways that would not identify them. Achieving this understanding may take a robust public education campaign.

Researchers

Most of our knowledge of social and behavioral determinants of health is derived from specific research projects (e.g., cross-sectional phone surveys, cohort designs). Including measures of social and behavioral determinants of health into EHRs provides unique opportunities and challenges for researchers. Integrating measures of social and behavioral determinants of health with both historical and concurrent clinical data will enable researchers to test in diverse populations important hypotheses about the strength of relationships with various indices of health, timing of their influence across the life span, and pathways that connect these domains with health, informing interventions and treatment. It would also enable the identification of social and behavioral subgroups that would benefit from specific current treatments and interventions.

Shortcomings in existing measures pose both challenges and opportunities. As mentioned earlier, some of the measures for domains are not ready to be used at present. The committee's analysis provides some initial ideas about which aspects of given measures need better documentation. Researchers can make important contributions by developing standards on how to best collect data, establishing which measures are well suited for capturing valid, actionable information and minimizing the burden and increasing the feasibility of collecting information on social and behavioral determinants of health. This should include best practices for asking patients about sensitive issues or how to collect the data (i.e., self-report on a computer, in-person, or by a social worker). Where appropriate, research can be used to develop metrics for the domains. Because the measures need to be useful clinically, some domains require developmental studies regarding effective ways to change social and behavioral factors that lead to improved health. For example, studies on how to improve psychological assets, such as optimism, conscientiousness, and self-efficacy, are needed along with documentation on how such changes affect health and health care utilization.

Some of the challenges that researchers will face in tackling this research agenda simply reflect current challenges, but with added complexity with the interface with EHRs. Maintaining patient privacy and confidentiality in the process of integrating data among a number of sources is paramount. Some of the data are particularly sensitive and require special protections. Inclusion of patients into research teams and internal review boards may help to develop solutions to these issues and would be helpful to all concerned. Finally, research on social and behavioral determinants of health using EHRs will require collaborations among social scientists, informaticians, health services, and public health researchers. As with any interdisciplinary work, such collaboration introduces complexity and challenges, but it results in better solutions to important health problems of our country.

Payers and Employers

Payers and employers have a keen interest in the health of their populations. Many rely on health risk appraisals (HRAs) to inform their employees about social and behavioral risks and risk-reduction strategies and to guide their programs and benefit plans. Several of the measures not meeting the criteria for usefulness and readiness for EHRs may be useful in HRAs. The availability of widely accepted standard measures of the social and behavioral determinants of health should greatly enhance the value of HRAs for use in employee wellness programs by enabling them to make more accurate risk assessments and adjustments.

Payers and employers will need to address individual and special populations' concerns about privacy, especially for sensitive domains. In addition, they may be challenged as they gain knowledge of these determinants of health in their enrolled and employed populations because the resulting awareness of these risks may increase pressures to create programs to improve health that address these and other determinants of health. Employers and payers will need to have the ability to prioritize efforts to address social and behavioral determinants of health and to offer effective programs incorporating social and behavioral determinants of health in their wellness and health promotion programs.

TABLE 7-1 Opportunities and Challenges to Integrating Social and Behavioral Determinants of Health into EHRs for Various Stakeholder Groups

Stakeholder Group	Opportunities	Challenges
Office of the National Coordinator for Health Information Technology (ONC)	• New standards for data domains that have received little attention • Guidance for Meaningful Use regulations	• Monitoring the process and outcomes of implementation • Ongoing review to identify new domains and measures

continued

TABLE 7-1 Continued

Stakeholder Group	Opportunities	Challenges
Research sponsors (e.g., NIH, PCORI, AHRQ)	• New types of data in standard form enables novel avenues of research • Informs data standards for the national data networks	• Funding needs for new avenues of research enabled by expanded data and for basic research on social and behavioral determinants of health (SBDH) • Support for interdisciplinary team approaches • Need for cross-institute and cross-unit collaboration
Quality improvement organizations (e.g., AHRQ, NQF, NCQA, Joint Commission)	• Additional information for health care quality and disparity reports • Better risk-adjustment models, including SBDH data	• Obtaining necessary data from health care organizations • Evaluating EHR specifications for SBDH-related quality measures
Center for Medicare & Medicaid Innovation (CMMI)	• Expands available practice-based data	• Integrating SBDH into CMMI's demonstration and evaluation portfolio
EHR vendors	• Provides guidance on systematic inclusion of a standard set of SBDH • Offers insights that may guide current or planned population health product offerings	• New EHR functionality needed to geocode residential addresses and link to external data sources • Building SBDH data capture capabilities that comport with clinical workflows • New ways of analyzing and visualizing SBDH data to support provider population health goals
Health care systems and accountable care organizations	• Standard data for managing individual and population health • Better risk adjustment for quality assessment and payment	• Changes to workflow • Changes in clinical information systems to capture, store, and report data • Providing services to address SBDH needs

TABLE 7-1 Continued

Stakeholder Group	Opportunities	Challenges
Health professionals	• More comprehensive profile of patients' health and life conditions • Standard data and language • Facilitate shared decision making	• Requires new types of clinical interventions • Changes to workflows • Increased time demands • Additional training on use of SBDH data
Patients and patient advocacy groups	• More effective patient-centered care • Facilitate shared decision making • Less redundant information reporting	• Privacy concerns • Discomfort reporting sensitive information • Increased time • Lack of understanding of reason for reporting
Public health (Centers for Disease Control and Prevention, state, local and territorial public health departments)	• Enhance population health management capabilities • Strengthen relationships with the health care sector • New insights of connection between SBDH and morbidity and mortality within community	• Adding mapping methodologies to take advantage of geocoded data • Develop new relationships with health care organizations • Privacy concerns
Researchers	• SBDH data integrated with rich clinical data • Standardization of measures and complete panel • Expanded opportunities for collaborations among social scientists, informaticians, health services, and public health researchers	• Institutional review board (IRB) issues, including protecting patient privacy • Linkage to external data sources • Inclusion of patients in research teams
Payers and employers	• Standard measures for health risk appraisals and better risk adjustment • Better health management of enrolled and employee population	• Privacy and patient discomfort concerns • Need for programs addressing SBDH identified in health risk appraisals

CONTINUING REVIEW OF MEASURES

The range and characteristics of measures available to assess the social and behavioral determinants of health are likely to expand in the coming years. The rapid pace in developing new methods for capturing internal states, health-related behaviors, and self-reports on a wide range of characteristics and experiences will undoubtedly yield new measures within a relatively short time. There is no current forum or process for evaluating results of ongoing research and reviewing recommendations of social and behavioral determinants of health that meet acceptable criteria for inclusion in EHRs.

COMMITTEE FINDINGS AND RECOMMENDATIONS

The recommendations made by the committee in Chapter 5, set forward a coherent, parsimonious panel of social and behavioral domains and measures that should be included in all EHRs. In brief, the committee recommended use of standard measures for four domains that are already being regularly collected (race and ethnicity, tobacco use, alcohol use, and residential address), and the addition of eight additional domains (educational attainment, financial resource strain, stress, depression, physical activity, social isolation, intimate partner violence [for women of reproductive age], and neighborhood median-household income).

The committee believes that, taken together, these provide a set of psychosocial vital signs whose inclusion in the EHR will have sufficient benefit to justify the additional time and effort to collect the data, and the added demands to use the resulting information to improve care. The committee further identified three recommendations for future directions in the field of capturing recommended social and behavioral domains and measures for EHRs as follow.

Finding 7-1: Standardized data collection and measurement are critical to facilitate use and exchange of information on social and behavioral determinants of health. Most of these data elements are experienced by an individual and are thus collected by self-report. Currently, EHR vendors and product developers lack harmonized standards to capture such domains and measures.

> **Recommendation 7-1: The Office of the National Coordinator for Health Information Technology's electronic health record certification process should be expanded to include appraisal of a vendor or product's ability to acquire, store, transmit, and download self-reported data germane to the social and behavioral determinants of health.**

Finding 7-2: The addition of social and behavioral data to EHRs will enable novel research. The impact of this research is likely to be greater if guided by federal prioritization activities.

> **Recommendation 7-2: The Office of the Director of the National Institutes of Health (NIH) should develop a plan for advancing research using social and behavioral determinants of health collected in electronic health records. The Office of Behavioral and Social Science Research should coordinate this plan, ensuring input across the many NIH institutes and centers.**

Finding 7-3: Advances in research in the coming years will likely provide new evidence of the usefulness and feasibility of collecting social and behavioral data beyond that which is now collected or which is recommended for addition by this committee. In addition, discoveries of interventions and treatments that address the social and behavioral determinants and their impact on health may point to the need for adding new domains and measures. There is no current process for making such judgments.

> **Recommendation 7-3: The Secretary of Health and Human Services should convene a task force within the next 3 years, and as needed thereafter, to review advances in the measurement of social and behavioral determinants of health and make recommendations for new standards and data elements for inclusion in electronic health records. Task force members should include representatives from the Office of the National Coordinator for Health Information Technology, the Center for Medicare & Medicaid Innovation, the Agency for Healthcare Research and Quality, the Patient-Centered Outcomes Research Institute, the National Institutes of Health, and research experts in social and behavioral science.**

CONCLUSION

With the passage of the Patient Protection and Affordable Care Act of 2010 the United States has begun to expand health coverage to millions of uninsured Americans, and increased attention has been given to population health management. Currently, the limited availability of social and behavioral determinants of health in EHRs limits the capacity of health systems to address key contributors to the onset and progression of disease. Addition and standardization of a parsimonious panel of social and behavioral measures into EHRs will spur policy, system design, interoperability, and innovation to improve health outcomes and reduce health care costs.

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A

Domains Reviewed But Not Selected for the Candidate Set

This appendix includes information about the domains that the committee reviewed but did not select to be among the candidate set of domains to be included in all electronic health records (EHRs) as part of its Phase 1 task. What follows provides domain descriptions, including examples of each one's association with health, along with illustrations of useful interventions for individuals or the population and priorities for research. The committee reviewed the evidence for these domains and found that the evidence of the association with health and usefulness was less compelling than that for the candidate domains included in Chapter 3. Table A-1 shows all the domains reviewed by the committee and how the committee voted to rank them. Three stars in the first column indicate a strong relationship between that domain and health, two stars represent a moderate association, and one star indicates weak or insufficient evidence to indicate a relationship. The subsequent columns summarize the usefulness of having information on a given domain in relation to treating individual patients, in relation to managing the health of a population, and for research purposes. Three stars stand for the committee's judgment that a measure of the domain would be highly useful for a given focus, two stars that it would be moderately helpful, and one star that it would have unproven or minimal value. All of the domains colored in blue became part of the committee's candidate set of domains for which measures were identified in Chapter 4.

The committee's work leading to its decision to exclude the indicated domains is described here to help guide future efforts that consider the addition of social and behavioral determinants of health domains in EHRs. The domains are not listed in order of priority but, instead, are organized

TABLE A-1 Applying Committee Criteria to Domains: Strength of Evidence and Usefulness

Domain	Strength of Evidence of Association with Health	Usefulness		
		Individual	Population	Research
Sociodemographic				
Sexual orientation	***	***	*	***
Gender Identity	***	*	*	***
Race/Ethnicity	***	***	***	**
Country of origin/U.S. born or non-U.S. born	***	***	***	***
Education	***	***	***	**
Employment	***	***	***	**
Financial resource strain: Food and housing insecurity	***	**	***	**
Psychological/Cognitive				
Health literacy	**	***	***	***
Stress	***	***	***	***
Negative mood and affect: Hostility and anger	***	*	*	***
Hopelessness	*	*	*	**
Depression and anxiety	***	***	***	**
Psychological assets: Conscientiousness, patient empowerment/activation, optimism, self-efficacy	***	***	***	***
Coping, positive affect, life satisfaction	**	*	*	**
Cognitive function in late life	***	**	**	**

Behavioral				
Dietary patterns	***	***	***	**
Physical activity	***	***	***	**
Abuse of other substances	***	**	**	*
Tobacco use and exposure	***	***	***	*
Alcohol use	***	***	***	**
Sexual practices	***	*	*	**
Exposure to firearms	***	*	*	**
Risk-taking behaviors: Distractive driving and helmet use	**	*	**	**
Individual-Level Social Relationships and Living Conditions				
Social engagement and isolation				
Social connections and social isolation	***	***	***	***
Social support: Emotional, instrumental, and otherwise	***	**	*	**
Exposure to violence	***	***	***	***
Work conditions	**	**	**	***
History of incarceration	**	*	*	***
Military service	***	**	*	***
Community and cultural norms: Health decision making	**	**	**	**

continued

TABLE A-1 Continued

Domain	Strength of Evidence of Association with Health	Usefulness		
		Individual	Population	Research
Neighborhoods and Communities				
Compositional characteristics				
Socioeconomic characteristics	***	***	***	***
Racial/ethnic characteristics	**	**	***	***
Contextual characteristics				
Environmental pollutants and other hazards	***	**	**	**
Availability of nutritious food options	**	**	**	***
Transportation, parks, and open spaces	**	**	**	***
Health care and social services	**	**	**	***
Educational and job opportunities	**	**	**	**

NOTE: The shaded and bolded text reflects the domains considered to be candidate domains for consideratin to add to all EHRs. *** = strong relationship or highly useful, ** = moderate association/utlity, * = weak or insufficient relationship/value.

by the committee's outline in Chapter 2, which ordered domains according to the types of data they represented. Of note, after the committee's review, the Office of the National Coordinator for Health Information Technology (ONC) requested comments on whether its certification program should require EHRs to be capable of collecting several of the domains that the committee considered (HHS, 2014).

The following domains were considered and are included in the list below in the general context of the domains identified in Table 2-1:

Sociodemographic Domains
Gender identity

Psychological Domains
Negative mood and affect: Hostility and anger, hopelessness
Cognitive function in late life
Positive psychological asset: Coping, positive affect, life satisfaction

Behavioral Domains
Abuse of other substances
Sexual practices
Exposure to firearms
Risk-taking behaviors: Distractive driving and helmet use

Individual-Level Social Relationships and Living Conditions Domains
Social support: Emotional, instrumental, and other
Work conditions
History of incarceration
Military service
Community and cultural norms: Health decision making

Neighborhoods and Communities Contextual Characteristics
Environmental exposures: Air pollution, allergens, other hazardous exposures
Availability of nutritious food options
Transportation, parks, and open spaces
Health care and social services
Educational and job opportunities

GENDER IDENTITY

Gender identity is a person's subjective sense of his or her gender, which may or may not be the same as that person's gender at birth. Shortly after birth, gender is determined on the basis of external genitalia or genetic tests. However, individuals may not feel that they are truly the gender to which they were assigned or determined to be at birth; this is referred to as "gender dysphoria" (APA, 2013). For example, persons born male may believe themselves to be female, persons born female may feel themselves to be male, and persons may feel that they are neither male nor female. The last group may refer to themselves as being intersex or hermaphrodites.

People who feel themselves to be a gender different from their assigned sex may choose to alter their physical appearance to fit the gender they feel themselves to be. Such individuals may make physical alterations that range from outwardly dressing as the gender they believe themselves to be to taking hormonal treatments and undergoing surgical procedures to physically change their appearance (currently known as "sexual reassignment"). Individuals who are in transition from one gender to another may refer to themselves as "transsexual" or "transgender" (i.e., transgender male to female or transgender female to male).

Evidence of Association with Health

Persons who feel themselves to be a gender different from their genetic sex may experience psychological distress beginning in childhood until such time that they are able to transform their life to fit their self-perceived gender (de Vries et al., 2011). Those who are transitioning from their genetic sex to their perceived gender may seek out health care professionals to receive hormone treatment or sexual reassignment. Persons who do not feel that they can access medical care because of fear of the response to their request for sexual reassignment, discrimination, or a loss of privacy or because of financial strain may use unsafe methods to change their physical appearance. For example, individuals may illegally obtain hormone treatments without proper medical advice or follow up. Hormone treatments have known side effects (e.g., estrogen increases the risk of thromboembolism), and therefore it is important that persons taking hormone treatment be under the care of a physician. Certain transgender persons—specifically, male-to-female transgender individuals—have been shown to be at particularly high risk of HIV infection due to their high-risk sexual behaviors and injection drug use (Clements-Noelle et al., 2001). Data are lacking, however, about whether gender identity is a risk factor for other disorders such that diagnosis or treatment would be informed by knowledge of gender identity.

Usefulness

Understanding the health needs of this population could enable health care providers to provide more culturally appropriate health care and counseling and help patients with nonconforming genders from feeling alienated. Additionally, knowledge of whether a patient is taking hormone treatments allows health care providers to identify adverse side effects and may prevent adverse interactions with other medications. This requires the ability to identify transgender individuals. They are considered one of the least understood populations because of the lack of research on this population, and the committee could find no standard ways to assess transgender status.

Conclusion

The 2011 Institute of Medicine (IOM) Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities noted the dearth of research on transgender individuals (IOM, 2011). Conducting research on transgender health is difficult in part because it is a statistically rare event and unlikely to be adequately represented in general samples. It is estimated that 0.3 percent of the U.S. adult population are transgender (Gates, 2011). The 2011 IOM report thus recommended inclusion of questions on gender identity as well as sexual orientation in EHRs to facilitate research. They observed that the sensitivity of the issue and the "lack of knowledge by providers of how to elicit this information" are barriers to standard collection in population surveys. That committee, as well as speakers at a related IOM workshop, noted the need to develop valid, reliable measures (IOM, 2011, 2013a).

In sum, although the evidence of the association of gender identity with psychological distress and risk behaviors exists, it is relevant to a very small number of people, reducing its impact on population health. In addition, the same problems of sensitivity and lack of standard assessment that have limited research efforts pose barriers to use in EHRs. The committee realized that this poses a "chicken and egg" dilemma; better research is needed to develop feasible validated measures of gender identity to meet the criteria for inclusion in all EHRs, while inclusion in EHRs could help provide the evidence base for developing such a measure. The committee concluded that including gender identity in every individual's EHR at this time would not result in sufficient improvements in overall clinical care or population health to justify its inclusion. Instead, the committee concluded that more work needs to be done on the assessment tools. In the meantime, health systems with large numbers of persons who are transgender should include the best available questions to determine gender identity, and clinical care teams and health settings need to be sensitive to gender identity in their interactions with patients.

NEGATIVE MOOD AND AFFECT: HOSTILITY, ANGER, HOPELESSNESS

Hostility and Anger

Anger is considered to be an emotional state that consists of feelings ranging from mild annoyance to extremes of rage (Chida and Steptoe, 2009). In contrast, hostility is a more enduring attitude of mistrust of others that is quite stable across long periods of time, from young adulthood into old age. Aggression is defined as behaviors attempting to inflict verbal or physical harm on others; it is not necessarily accompanied by anger. While anger varies across time and situations, measures of anger frequency are relatively stable. Anger expression is a characteristic style of expressing anger, usually categorized into the outward expression of anger versus the inhibition of anger.

Evidence for Association with Health

Anger and hostility have been studied in the context of the risk for hypertension and coronary heart disease. In a meta-analysis of 25 studies of initially healthy populations and 19 studies of coronary heart disease patients, anger and hostility measures predicted future coronary heart disease in both types of populations (Chida and Steptoe, 2009). There was some suggestion that the effects were stronger in men than in women (see also the work of Low et al., 2010). In subgroup analyses, anger expression styles were not related to heart disease; however, individuals who score high for anger and hostility typically have risky health behaviors, including physical inactivity, cigarette smoking, and obesity.

Usefulness

Knowledge of a patient's level of hostility and anger could potentially identify patients, especially men, who are at high risk for cardiovascular disease. However, the evidence of usefulness to the individual and population was considered to be insufficient by the committee. This domain was ranked as useful for research purposes.

Conclusion

Anger and hostility predict future heart disease and are associated with risky health behaviors. There is some suggestion that the associations are stronger in men than in women. The committee considered whether it should be measured in men only, but it preferred EHR assessment that is designed to be universal. Because there are limited evidence-based interventions available to the clinical team if a patient scores high on anger or hostility, the committee elected not to include it as one of its candidate domains.

Hopelessness

Hopelessness overlaps conceptually with extremes of pessimism and accompanies severe depression. It refers to an affective-cognitive state in which a person expects bad outcomes in the future, believing that there are few alternatives to make things better, and has a tendency to give up.

Evidence of Association with Health

Several epidemiological analyses have shown that hopelessness is related to mortality from cardiovascular disease and cancer and the incidence of myocardial infarction in men, independent of depression and numerous covariates (Everson et al., 1996). Furthermore, a feeling of hopelessness can be a marker for suicide risk.

Usefulness

It is not clear to the committee that measures of hopelessness are useful for inclusion in the EHR, independent of depression, pessimism, optimism, and coping. The usefulness of inclusion of measures of hopelessness may be in further screening of patients who are depressed, pessimistic, and avoidant copers.

Conclusion

Hopelessness overlaps conceptually with extremes of pessimism and is a symptom of depression. There are a number of epidemiological studies showing that hopelessness is associated with cardiovascular and cancer mortality and myocardial infarction in men. Given the conceptual overlap of hopelessness with other negative emotions and attitudes, including epidemiological data on the associations of optimism/pessimism with depression, and stronger and more complete data on the relationship of other variables such as optimism/pessimism and depression with health outcomes, the committee elected not to include hopelessness as one of its candidate domains.

COGNITIVE FUNCTION IN LATE LIFE

As life expectancy is lengthening, cognitive function in late life is increasingly recognized as a factor that has an important effect on health and health care utilization. Age-related impaired cognitive function is increasingly prevalent as people advance into late life. Conditions like Alzheimer's disease and other dementias are extremely rare before age 65 years; 5.0 percent of individuals between the ages of 71 and 79 years; 24.2 percent of individuals between the ages of 80 and 89 years; and 37.4 percent of individuals aged 90 years and older have dementia (Plassman et al., 2007).

Evidence of Association with Health

Alzheimer's disease and related disorders are related to mortality risk, and the effects of such diseases on mortality are greater in younger age groups. In addition, lower levels of cognitive function and the presence of dementia present difficulties for individuals adhering to therapies, reporting symptoms reliably, and seeking appropriate care. Cognitively impaired individuals are more likely to become lost to follow up and to become socially isolated.

At present, there are limited interventions or treatments to correct or effectively treat the cognitive impairment in late life.

Usefulness

Cognitively impaired individuals typically present to health care providers with unrelated problems. It may be useful to their providers in making diagnoses or recommending treatment to take into account possible problems in cognitive functioning. The availability of accurate data about cognitively impaired individuals is also useful from a public health perspective.

Conclusion

Measures of cognitive function are most relevant for older adults and would not be useful to include in all EHRs. Because of this, it does not fully meet the individual patient health management criteria. The committee also notes that the U.S. Preventive Services Task Force (USPSTF) does not recommend screening at this time even in the older population. In addition, the results of brief cognitive screening tests can be affected by education levels, ethnicity, and language—among other personal characteristics—and be misconstrued. Thus, the committee elected not to include cognitive function in late life as one of its candidate domains.

POSITIVE PSYCHOLOGICAL ASSETS: COPING, POSITIVE AFFECT, AND LIFE SATISFACTION

Coping

Coping is defined as the processes that people use to manage the demands created by stressful circumstances. These processes are typically aimed initially at changing the stressful circumstances in some way (i.e., problem-focused coping), and, if that is not possible or successful, at managing the emotional sequelae of the stressor (i.e., emotion-focused coping). Anticipatory coping occurs when a person preemptively plans how to handle potentially stressful circumstances, as opposed to coping after the occurrence of the stressor. Coping processes are thought to be specific to the stressful circumstances but may also be generalized across situations. The latter perspective considers coping to be a psychological trait. Scales are available to measure multiple types of coping for both specific situations and in general across situations. These are usually organized into highly specific types of coping (e.g., reappraisal, seeking support) and are then summarized into higher-level concepts.

Evidence of Association with Health

The form of coping used in a given situation is associated with changes in health and adjustment to serious illness. As summarized by Taylor and Stanton (2007), use of problem-focused approach coping methods is associated with better health and positive adjustment, provided that the stressor is potentially controllable, while avoidance coping, especially in relation to long-term stressors, may increase distress and poor adjustment. Avoidance coping may preempt the use of more effective coping methods, can involve risky behaviors, and may foster intrusive thoughts or rumination. The data are more consistent for the negative impact of avoidance coping than for the positive impact of approach coping.

Usefulness

Coping resources and processes affect mental and physical health. Research directed at improving coping processes has not seen adequate translation into strategies for psychosocial intervention. There does appear to be some suggestive evidence that coping resources can be altered with psychosocial intervention. Among individuals undergoing stressful circumstances, interventions that address particular skills and coping deficits may hold more promise than attempts to directly change a person's disposition. Future research will be guided by increasing understanding of the environmental and genetic inputs to developing coping skills (Taylor and Stanton, 2007).

Conclusion

Coping skills—in particular, use of avoidance coping—are associated with adjustment to illness. However, the health impact of coping skills varies with the nature and duration of the stressor, which makes assessment of coping more complex. Empirical validation of interventions to foster better coping is needed. Therefore, along with the concern about complexity of measuring coping and questions about usefulness given current data, the committee elected not to include coping as a candidate domain.

Positive Affect

Positive affect is defined as the extent to which an individual experiences pleasurable feelings, including joy, happiness, and cheerfulness. It can be measured as a general or an immediate affective state. Common measures are obtained through the use of a questionnaire with a list of adjectives. Respondents are asked the extent to which they feel—usually, or at the present time—the affect identified by those adjectives.

Evidence of Association with Health

Chida and Steptoe (2008) conducted a meta-analysis of positive psychological well-being and survival through the use of subgroup analyses specifically examining the role of positive affect. While studies of healthy participants found that positive affect protected individuals from early mortality, studies of patients with serious illnesses did not find a beneficial effect. Similarly, a review conducted by Pressman and Cohen (2005) concluded that positive affect was generally related to a lower risk of mortality and morbidity; the association was less clear among those with severe illness, a conclusion similar to that reached by Chida and Steptoe (2008).

Usefulness

Positive affect appears to be less useful in a clinical context than a measure of negative affect such as depression. Positive affect may be more helpful to assess in response to treatment, but this has not been tested. Measures of happiness and positive feelings are more useful for research purposes.

Conclusion

Positive affect appears to be related to lower risk of mortality and morbidity among those who are initially healthy, but not necessarily among patients with serious illness. Given that this domain is a relatively new focus of investigation and the inverse association of positive affect with negative emotions, the committee believes that evaluating depression is more useful for individual patient health management than assessing an individual's positive affect. At a later date, there may be additional evidence that monitoring positive affect may be helpful to chart changes in response to treatment. Therefore the committee elected not to include positive affect as a candidate domain.

Life Satisfaction

Life satisfaction refers to the extent to which individuals judge their overall quality of life to be satisfactory. Items indicating life satisfaction can be framed temporally, that is, the quality of life in the past and in the present and the quality of life anticipated in the future. The most common measure of life satisfaction uses a five-item scale of quality of life in the past and in the present, but a more recent version also includes items oriented toward the future.

Evidence of Association with Health

Several prospective studies have reported an association between life satisfaction and reduced heart and cardiovascular disease (Boehm et al., 2011; Shirai et al., 2009) and life satisfaction with mortality in men but not in women (Lacruz et al., 2011). Life satisfaction may predict subsequent major depression and poor mental health (Rissanen et al., 2011). Most of the available literature reviews on positive psychological function combine life satisfaction indicators with other measures of well-being (Lyubomirsky et al., 2005). Thus, it is difficult to isolate the impact of life satisfaction.

Usefulness

The measure of life satisfaction was seen by the committee as moderately useful for research purposes. The domain was seen as less helpful for the individual and the population at this time.

Conclusion

There is evidence indicating that there is an association between life satisfaction and health, but the committee viewed this to be only a moderate association. Most of the evidence combines life satisfaction's measures with others measures of well-being. Thus, it is difficult to isolate the impact of life satisfaction. This domain predominantly was seen as useful to research criteria. For these reasons, the committee elected not to select life satisfaction as a candidate domain.

ABUSE OF OTHER SUBSTANCES

Substance abuse includes the abuse of illegal drugs as well as the misuse of household substances and legal substances (e.g., prescription drugs, aerosols, and glue) (HHS, 2013). Substance abuse occurs in individuals over the range of the life span from adolescence to adulthood, and the substances most frequently abused include marijuana, hallucinogens, cocaine, opiates, amphetamines, inhalants, and methamphetamines (NIDA, 2011). When taken as directed and in moderation, prescription drugs are safe and can help manage mental, biological, and physical symptoms. However, regularly taking medication in a way that differs from what a doctor prescribed is referred to as prescription drug abuse. This can happen in several ways, including a patient taking a medication that has not been prescribed for her or him, taking too large of a dose, or taking a medication with the intention of getting high (NIH, 2014).

Evidence of Association with Health

In 2010, there were nearly 40,000 deaths from drug overdose, a majority of which were unintentional (CDC, 2013). Examples of the association of abuse of other substances with health are listed below: pregnant women who use drugs have been found to be more likely to receive little to no prenatal care during pregnancy (Roberts and Pies, 2011); cocaine, methamphetamine, or heroin users who used the substance over the course of their lifetime were found to have higher systolic and diastolic blood pressure (Akkina et al., 2012); driving under the influence of marijuana was found to be associated with a significant increase in fatal motor vehicle accidents (Asbridge et al., 2012); perpetrators of interpersonal violence were found to be significantly more likely to use methamphetamine, alcohol, and cocaine than the victims were (Ernst et al., 2008); and after alcohol and marijuana, prescription and over-the-counter drugs have been found to be the most commonly abused substances in adolescents ages 14 years and older (NIDA, 2012).

Usefulness

In 2008, the USPSTF stated that evidence of the benefits of screening individuals in late childhood and early adolescence about illicit drug use in a clinical setting is insufficient (USPSTF, 2008). However, the comorbidity of drug use/dependence and psychiatric conditions suggests integrated treatment by behavioral health care specialists (Havens et al., 2005). The committee rated usefulness for individual and population health to be moderate and for research to be low, given the difficulty of accurately collecting the information.

Conclusion

There is strong evidence of an association between substance abuse (e.g., illegal drug use, misuse of prescription drugs) and health. This is a growing area of concern within the health system, especially for those individuals who are misusing prescription drugs. As stated, earlier in its deliberation the committee acknowledged the complexity and the sensitivity issues surrounding the collecting of information on illegal substance abuse and legal substance misuse. The U.S. health care industry has yet to resolve the problem of maintaining an accurate medication administration list on patients, which compounds the challenge of exchanging patient drug information among multiple providers and detecting patient prescription drug misuse. In addition, capturing accurate drug use information from individual patients during a clinical encounter is challenging. For these reasons, this domain did not meet the criteria for usefulness as a measure for individual and population health management. Thus, the committee did not select abuse of other substances as a candidate domain.

SEXUAL PRACTICES

Sexual practices refer to the specific ways that people have sex with themselves or with others. It is related to the concept of sexual orientation, as certain practices are associated with having a particular sexual orientation (e.g., heterosexual men are likely to engage in vaginal intercourse, whereas men who are exclusively gay are not). However, even when people of the same sexual orientation are considered, tremendous variations in sexual practices exist. Sexual practices also include behaviors that may increase or decrease the health consequences of the behavior, such as condom use, partner selection, and drug use during sex.

Evidence of Association with Health

A large number of diseases referred to as sexually transmitted infections are known to be related to sexual practices. These diseases include, for example, AIDS, syphilis, gonorrhea, human papillomavirus infection, chlamydia infection, pelvic inflammatory disease, trichomoniasis, hepatitis, lymphogranuloma venereum, chancroid, herpes simplex virus, scabies, and pubic lice (CDC, 2010). Condom use is known to markedly decrease the likelihood of transmission of these infectious diseases. If they are untreated, some of those infections (e.g., HIV infection, syphilis) can cause serious morbidity, and if they are left untreated they can cause mortality. The prevalence of those infectious diseases affects not only the health of the individual but also the health of the community through sexual transmission to others. Some of those infections are transmissible to an unborn fetus (e.g., HIV infection, syphilis, hepatitis B and C, gonorrhea). Sexually transmitted infections are known to be more frequent among gay and bisexual men than among heterosexual men and women, are higher among younger persons than older persons, and are higher among African Americans and Latinos than among non-Latino whites (CDC, 2011).

Unprotected vaginal intercourse between a fertile man and a fertile woman may lead to unintended pregnancy. Depending on the circumstances, this may be a desirable or an undesirable outcome, depending on whether the pregnancy is wanted or unwanted. Pregnancy among teenage girls may lead them to drop out of school, compromising their educational and economic potential (NCPTP, 2010). Sexual practices may also be a joyful human expression. A World Health Organization report describes sexual health as "sexual being in ways that are enriching, and that enhance personality, communication, and love" (WHO, 1975, p. 4, 2006a). An inability to engage in sexual activities may reflect physical disease (e.g., diabetes) or mental state (e.g., depression).

Usefulness

Collecting information on sexual practices is a highly sensitive issue. Having knowledge of patient sexual practices could enable health care providers to provide their patients with the appropriate screenings for sexually transmitted infections. For example, rectal cultures for gonorrhea can be done in people who engage in anal intercourse but do not need be done in persons who do not engage in that sexual practice. Guidance on the treatment of sexually transmitted infections from the Centers for Disease Control and Prevention states that as part of the clinical interview, health care providers should routinely and regularly ask their patients about their sexual history to better reduce risk (CDC, 2010, p. 2). However, the committee rated the usefulness to the individual and population as low, given the likelihood of accurately collecting the information.

Health care providers can provide their patients with appropriate family planning counseling. In particular, adolescents may have incorrect information about the likelihood of pregnancy or sexually transmitted infections involved with certain sexual practices (e.g., transmission of gonorrhea through oral sex). This was viewed by the committee as a good practice by the clinical team but not relevant to inclusion in the EHR.

Conclusion

The evidence of association between sexual practices with health is clear. Health care providers can use this information in developing treatment and intervention plans. However, sexual behavior is for some people a very personal and private topic. Routinely asking all individuals about sexual practices as part of an EHR was also seen as controversial. Further, the committee noted that determining the riskiness of sexual practices for health can require asking many questions about the type of sexual acts, the partners involved, whether protection (e.g., condoms, dental dam) was used, and whether substances concomitantly were used. This would require many questions and complicated skip logic that would not be appropriate for an EHR.

EXPOSURE TO FIREARMS

Firearm ownership refers to the personal ownership of a firearm as well as living in a household with a firearm(s) (Hepburn and Hemenway, 2004; IOM and NRC, 2013; NRC, 2004; Wiebe, 2003). The manufacturing, distribution, carrying, transport, selling, acquisition, and use of firearms are regulated by federal, state, and local laws. Interpersonal violence is a related concept. Some interpersonal violence literature addresses the relationship between firearms and coercive behaviors, psychological abuse, and child abuse (physical, sexual) (Howard et al., 2007; Ismail et al., 2007; Shields et al., 2012; Smith and Ford, 2010). Public health injury programs and firearm violence prevention advocacy organizations have worked for several decades to pass legislation aimed at restricting firearm acquisition, imposing waiting periods for acquiring firearms, requiring firearm registration and licensing, creating zero tolerance for the presence of firearms in schools, and preventing child access to firearms. Firearms per se are not a social determinant of health. It is the contexts within which firearms are owned and used that often determine their relationship to injury and death and their being viewed as a social determinant.

Evidence of Association with Health

In 2010, approximately 18 percent of all injury deaths were caused by firearms, accounting for 31,672 firearm deaths, or 10.3 deaths per 100,000 individuals. Suicide (61.2 percent) and homicide (35 percent) were the major components of all deaths from firearm injury (Murphy et al., 2013). Grassel et al. (2003) found an association between handgun purchases and mortality from firearm injury. In general, the research suggests that there is an association between the presence of firearms in the household and homicide, in addition to unintentional injury from a firearm and a higher risk for homicides (Hepburn and Hemenway, 2004; Miller et al., 2006; Wiebe, 2003). Swahn et al. (2002) reported that 25 percent of U.S. adolescents reported that they have easy access to either alcohol or a gun in the home, which suggests that efforts to increase parental awareness of these facts is needed.

Usefulness

The Community Preventive Services Task Force (the Task Force) reviewed evidence examining the effects of selected federal and state firearms laws and their effects on violence-related population health outcomes as well as on other outcomes, such as school expulsion, property crime, and apprehension of criminals (TFCPS, 2005). The Task Force identified population health interventions that are effective at saving lives, increasing the life span, and improving quality of life. To date, the Task Force has found that the scientific evidence on the following types of firearm interventions is insufficient to recommend that community health interventions be implemented to prevent them: bans on specified firearms or ammunition, restrictions on firearm acquisition, waiting periods for firearm acquisition, firearm registration and licensing of firearm owners, laws on carrying concealed weapons, child access prevention laws, zero tolerance of firearms in schools, and combinations of firearms laws. It was unclear to the committee how useful a clinical intervention about firearm ownership could be. Further, it is a sensitive question to ask and use in an EHR, although there could be research benefits from having this knowledge.

Conclusion

The evidence of association between misuse of firearms and adverse health outcomes is apparent. Firearms are associated with unintentional injuries, suicides, and homicides. However, this domain does not fully meet the criteria for usefulness as a measure for individual screening or counseling because of the limited interventions available to the clinical team. The evidence does not support use as a screening instrument and also does not support ability to screen and counsel in primary care settings. Exposure to firearms is an important indicator for understanding injury statistics, but population-level data can be gathered as readily from other sources (e.g., crime reports) as from EHRs. This domain is also useful for studying relationships between individual characteristics and exposure to firearms. Because of the lack of a research base, the impracticality of screening in primary care settings, and the evidence of appropriate interventions, the committee elected not to select exposure to firearms as a candidate domain.

RISK-TAKING BEHAVIORS: DISTRACTIVE DRIVING AND HELMET USE

Risk-taking is defined as engaging in behaviors having at least one uncertain outcome (Fischoff, 1992). Risk-taking has both psychological and behavioral traits. In this report the committee focuses on distractive driving and helmet use. Risk-taking is particularly prevalent among operators of motor vehicles. In the general population, 47 percent of men and women and 34 percent of teens ages 16 or 17 years say that they have sent or read text messages while driving (Madden and Raine, 2010). A study of college students revealed that 74 percent engaged in texting while driving, 52 percent said that they texted while driving on a weekly basis, and 17 percent accessed the Internet while driving (Cook and Jones, 2011). Even under perfect driving conditions, text messaging has been demonstrated to have detrimental effects on such driving behaviors as lane maintenance, speed maintenance, and shifts of attention (McKeever et al., 2013). Individual risk-taking behaviors are often influenced by the risk-taking behaviors of others. Among U.S. teenagers fatally injured between 1995 and 2000, driver seat belt use declined as the number of teenage passengers increased but increased when at least one passenger was older than 30 years of age (McCartt and Northrup, 2004). In the state of Hawaii, passengers were found to be 70 times more likely not to be wearing a seat belt if the driver was also not wearing a seat belt than if the driver was wearing a seat belt (Kim and Kim, 2003).

Head injuries are the principal cause of death and disability among motorcyclists, and injuries often require long-term rehabilitation and specialized medical care. Helmet use while riding a motorcycle or a bicycle is the single most effective way to reduce these fatalities and lessen the severity of injuries. Wearing a helmet has been shown to decrease the risk and severity of injuries among motorcyclists by approximately 70 percent and the likelihood of death by nearly 40 percent (WHO, 2006b).

Evidence of Association with Health

Examples of evidence of the association of distractive driving and helmet use with health include the following: one in six (17 percent) of adults who own a cell phone reported that their talking or texting, a distractive behavior, caused them to physically bump into another person or object (Madden and Raine, 2010); the recent rise in the volume of texting is believed to have contributed to the rise in fatalities because of distracted driving—more than 16,000 additional fatalities on the road from 2001 to 2007 (Wilson and Stimpson, 2010); texting while driving was a factor in 45 percent of motor vehicle fatalities in an autopsy series (Pakula et al., 2013); use of motorcycle helmets was associated with a reduced risk of death and head injury among motorcyclists who crashed (Lui et al., 2008); and wearing a bike helmet reduces the risk of life-threatening head and brain injury by more than 80 percent (OrthoInfo, 2011).

Usefulness

A small study that recruited 14- to 15-year-olds found that screening and a brief counseling intervention in a primary care setting resulted in a significant increase in helmet use (Ozer et al., 2011). Public education and legislation can be effective. From 1994 to 1998, bicycle-related head injuries in children declined by 45 percent in Canadian provinces and territories where legislation requiring helmet use was implemented, whereas the decline was 27 percent in areas without such legislation (Macpherson et al., 2002). For distractive drivers, effective enforcement of legislative bans on texting can deter drivers from engaging in this activity (Wilson and Stimpson, 2010).

Conclusion

The evidence of an association between risk-taking behaviors and health as reviewed was seen to be moderate. Social changes brought about by public health awareness and policy implementations have, in some instances, led to a decrease in the number of individuals engaging in risk-taking behaviors (e.g., more widespread use of helmets). However, further research is still needed to elucidate the best approaches to individuals who engage in distractive driving. The risk-taking behavior domain was rated moderately useful for population health management and research. However, the domain was rated minimally useful for individual patient management given the limited interventions available to the clinical team. Therefore the committee elected not to include risk-taking behaviors as a candidate domain.

SOCIAL SUPPORT: EMOTIONAL, INSTRUMENTAL, AND OTHER

Whereas social integration/isolation refers to the presence and quantity of social relationships, social support refers to one aspect of the content of these relationships: actual or perceived support, or benefit from supportive relationships. Analysts often distinguish between instrumental and emotional support and the perceived availability versus actual receipt of such support.

Evidence of Association with Health

Many small-scale studies and some larger population studies have found that social support is positively associated with health indicators. The association may reflect a direct/additive relationship and/or a buffering/interactive effect 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 and Wills, 1985; Cohen et al., 2007; Dour et al., 2013; Sarason et al., 1990a,b). The evidence mostly supports the health-protective effects of perceived and emotional support, with the effects of other forms of perceived support and its actual receipt being more complex or specific. The receipt of certain types of support under certain circumstances can even have deleterious effects on health (Rook, 1984; Rook et al., 2012).

Usefulness

Although one can briefly get a global sense of a person's perception of the availability of support, the assessment of social support is generally multifaceted and somewhat complex, posing problems, including the information in EHRs. Social support appears to play a role in the etiology of health problems and even more so in the course of such problems. Interventions seeking to prevent health problems or to facilitate recovery from or adaptation to them often include provision of social support. Information on social support could be valuable in both clinical practice and epidemiological research on the health of populations, but more evidence is needed.

Conclusion

The evidence of association between having social support and health is apparent. This domain, however, was seen as having moderate evidence of the criteria for usefulness as measured for the individual patient and research; it was also ranked low on the committee's criteria for population health management. Therefore the committee elected not to include social support as a candidate domain.

WORK CONDITIONS

Work conditions refer to the existing conditions and environment affecting labor in the workplace, including the amount of time spent at work, a worker's legal rights, the physical aspects of the work environment, and workers' responsibilities. The U.S. Congress, for example, defined the purpose of work conditions for the federal Occupational Safety and Health Act to be "to assure so far as possible every working man and woman in the Nation has safe and healthful working conditions."[1]

Evidence of Association with Health

Aspects of conditions in the workplace shape health. For example, exposure to physical risks and hazards, stress and poor mental health, and salary level or workplace benefits affect a person's ability to obtain nutritious foods, achieve adequate physical activity, locate healthy housing, and have access to medical care. Psychosocial aspects of work that influence health include work schedules, commuting conditions, how work is organized, social support at work, and discrimination in the workplace. Members of socially disadvantaged groups tend to have more work-related health risks, fewer health-related benefits, and lower-paying jobs (RWJF, 2011). Work stress has been associated with an increase in asthma (Loerbroks et al., 2010), lower back pain (Lau and Knardahl, 2008), and type 2 diabetes in middle-age women (Norberg, 2007). 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). Policies in the United States protect individuals from many, but not all, of these exposures. Negative employment experiences may create mental health problems particularly in midlife and suggest the need to consider the role of interventions to better reduce mental health disorders for these individuals (Burgard et al., 2013).

Usefulness

Public policies have improved working conditions; work environments are healthier, but disparities are still widespread in a variety of occupations. The clinical health team could identify groups of patients at risk for expo-

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[1] 29 U.S.C. 651, Section 2.

sures, such as housepainters and construction workers who may benefit from blood lead testing. The usefulness of this domain was seen by the committee as most helpful for research purposes, as the field would benefit from studies that suggest successful interventions that improve outcomes for patients. The committee noted that occupation hazards can be collected when collecting information on employment.

Conclusion

Overall, the evidence of association between work conditions with overall health was viewed by the committee as modest, and the evidence shows modest usefulness in having the information in all EHRs. Further research in this field is needed. The National Institute for Occupational Safety and Health (NIOSH) is currently developing standards that capture a patient's industry and occupation, including such items as work schedule and external causes related to injury and poisoning (NIOSH, 2014). When available, this may provide useful information. At this time, the committee elected not to include work conditions as a candidate domain.

HISTORY OF INCARCERATION

A history of incarceration refers to prior contact with the correctional system, including prisons and jails. When a person is incarcerated, health care is a responsibility of the correctional system. As described here, this domain refers to the receipt of health care upon release from prison or jail.

Evidence of Association with Health

Currently, more than 2.3 million individuals are incarcerated in the United States. It is estimated that on any given day, one in nine U.S. African American men ages 20 to 34 years is incarcerated, and one in three African American men is expected to be imprisoned at some point in his life, if rates of incarceration stay the same (PEW, 2008). Ninety-five percent of those individuals are ultimately released back into society, but most continue to cycle through the legal system throughout their lives (Wang et al., 2013). Incarceration is related to other social and behavioral factors that place individuals at higher risk for poor health, but it appears to be an independent risk factor. For example, a study conducted by Binswanger et al. (2007) found that former prison inmates were at high risk for death after release from prison. The first leading cause of death among these former inmates was drug overdose, followed by cardiovascular disease, homicide, suicide, cancer, motor vehicle accident, and liver disease, respectively (Binswanger et al., 2007). Interventions could therefore potentially help to reduce the risk of death after release from prison. A study of Medicare data from 2002 to 2010, which included both time in prison and shorter stays in jail, found that within 1 week of being released, 1 in 70 former inmates was hospitalized for an acute condition, and within 3 months, 1 in 12 former inmates was hospitalized (Wang et al., 2013). These included hospitalization for ambulatory care-sensitive conditions as well as conditions related to mental health and disease of the circulatory system (Wang et al., 2013).

Higher rates of hospitalizations for conditions requiring ambulatory care, such as diabetes mellitus, hypertension, and asthma, among former inmates may reflect higher rates of chronic medical conditions among individuals who have been released from incarceration. A history of incarceration is known to be an independent risk for incident cardiovascular disease (Wang et al., 2009). Alternative explanations include an acute decline in their health status due to barriers in obtaining medications or primary care immediately after release or a poor quality of health care during their incarceration.

Usefulness

Screening for a history of incarceration could potentially lessen preventable hospitalizations and improve access to care for chronic disease and mental health conditions, particularly during the period immediately after release from incarceration, when the individual may be most vulnerable. Several models of care targeting these individuals have focused on this transition (Wang et al., 2012). Collecting incarceration history can be highly sensitive, as individuals may question the value of these data in an EHR and not want to reveal information to a health system connected to their employer. Increased research was seen as a priority.

Conclusion

Incarceration is associated with a variety of social and behavioral factors that place one at risk for poor health, and history of incarceration has been shown to correlate with subsequent poor health outcomes. As the committee deliberated on this domain for consideration as a candidate in all EHRs, it determined it to be relevant for a specific population group (those who have been incarcerated), and it did not find the evidence base to suggest that all EHRs include these data. Therefore the committee did not select history of incarceration as a candidate domain.

MILITARY SERVICE

For health purposes, military service is a history of service in the armed forces of the United States or other nations, including the length and branch of service, the military occupation, the location and type of duty (e.g., in the United States or abroad with combat, combat support, or noncombat duties), and any ongoing illness, injury, limitation, or disability that began during military service.

Evidence of Association with Health

Military service is a significant risk factor for morbidity (both physical and mental), disability, and mortality (Baker et al., 2012; Foran et al., 2012; Greenberg and Rosenheck, 2009; LeardMann et al., 2013; Stander et al., 2007). The risks of mental disorders and suicide are significantly elevated for members of the military and veterans, even if they sustained no physical injuries or illnesses in the line of duty. Exposure to toxins is one of many risks. Approximately one-third of veterans of the 1991 Gulf War suffer from an array of long-term medically unexplained symptoms known as chronic multisymptom illness (IOM, 2013b).

Other health consequences of military service include traumatic brain injury and posttraumatic stress disorder (PTSD). PTSD is one of the most commonly diagnosed disorders in U.S. military personal. Comorbidity between disorders such as depression, PTSD, and substance abuse disorders is prevalent and poses complex health challenges (IOM, 2014b). At present, the time of military service relevant to this domain is mainly from 1950 to the present (IOM, 2014a). Given that Vietnam veterans are just now entering old age and large numbers of younger adults have served in Iraq and Afghanistan, the health risks of current military service and those of veterans remain substantial. Many veterans' health care, although not all, is covered through the Veterans Health Administration (VHA).

Usefulness

Given the significant health risks of military service, health care providers could benefit from knowing about their patients' military service, leading to better diagnoses and better treatment options, including the referral to VHA resources, which are not available to nonveterans. Much of this work is occurring within the U.S. Department of Veterans Affairs (VA) system. Specialty care is often necessary. A previous IOM committee recommends that the VA's EHR should prompt health care providers to ask patients about symptoms that characterize chronic multisystem illness (IOM, 2013b). A separate IOM committee recently concluded that there is sufficient evidence that exposure to roadside bomb blasts has contributed to the development of PTSD and concussion-related symptoms, such as persistent headaches. They recommended that the VA develop registries of blast exposures (IOM, 2014a).

Conclusion

There is evidence linking military service with poor health outcomes. However, it is unclear that military service alone is a risk factor; a greater risk is associated with combat experience, which would need to be measured as well. This domain was seen as less useful for individual health or population management because only about 13 percent of U.S. adults overall are veterans (Gallup, 2012); thus, the committee did not identify a strong need to include this domain in every patient's EHR. Many veterans are covered under the VA's health plan, and previous employment may be captured under the domain "employment," one of the selected candidate domains. In addition to employment, several of the measures that are already recommended for inclusion in the parsimonious panel will provide more direct indicators of risk. For example, the recommended screening for depression and stress would likely identify mental health issues that may have their roots in earlier military service and can be addressed without that knowledge. Therefore the committee did not select history of military service as a candidate domain.

COMMUNITY AND CULTURAL NORMS: HEALTH DECISION MAKING

Community and cultural norms often shape health-related decision making and behavior. One's immediate neighborhood and reference group, as well as the norms and values of the larger community, can encourage or dissuade specific behaviors such as diet, substance use, activity level, or health care seeking, and they may also provide support or increase exposure to conflict. Community norms may be particularly powerful in close-knit communities, including ethnic enclaves. In addition to the strength and cohesiveness of community and cultural norms to which patients are exposed, their cultural identities may affect their preferences and behaviors (Kwak and Haley, 2005).

Evidence of Association with Health

Community norms, including peer groups or social networks, have been shown to influence a person's perception of what he or she thinks is appropriate, correct, or desirable when making health decisions (Karasek et al., 2012). Social networks have been shown to have an important influence on a person's tobacco use and drinking patterns (Chen et al., 2001; Christakis and Fowler, 2008) and may operate, in part, through norms and social influence.

Usefulness

In treating an individual patient, health care providers may be able to reinforce health-promoting behaviors that are tied to community norms or be aware of cultural values and norms that may make it difficult for a patient to adhere to a prescribed regimen. Research on issues such as social determinants of smoking cessation could potentially inform interventions that promote health by altering the structural context (e.g., taxation policies) to complement more traditional individual behavior change approaches (Karasek et al., 2012). Knowing environmental norms can assist the health system in adapting policies and interventions that can positively influence their community's behavior. For example, laws and policies have been implemented in the majority of the United States prohibiting smoking indoors or in public spaces, lessening the likelihood that individuals will smoke.

Conclusion

Community and cultural norms and shared decision making undoubtedly play a role in health, but because there is no standard way to capture these in an EHR, the committee did not prioritize this domain in its review. A narrower focus on participatory decision making in the context of health care is more feasible, but this overlaps with other domains, such as patient engagement. As a result, the committee evaluated this domain as moderately associated to health and usefulness for all three uses identified and did not select community and cultural norms—health decision making—as a candidate domain.

NEIGHBORHOODS AND COMMUNITIES CONTEXTUAL CHARACTERISTICS

EHR systems collect clinical data about patients and their health problems. To obtain information on environmental factors that influence disease risk and disease outcomes, an EHR can be linked with a community information system (CIS). A CIS includes contextual information such as the geospatial distribution of grocery stores selling healthy food options, transportation resources, open spaces and parks, health care facilities, social services, and job and educational opportunities. In addition to those factors, a CIS can also contain information on population socioeconomic characteristics—so-called compositional factors—at the county, zip code, and neighborhood levels. Examples of geocodable domains that the committee found particularly compelling are listed in Chapter 3. The sections below provide further examples of the potential that geocodable information holds for communities.

EHR-CIS linkage entails address mapping of a patient's residence using geocoding software to obtain specific longitude and latitude coordinates. Once this is done, the patient's county, zip code, and census block of residence can readily be obtained. On average, counties in the United States have 100,000 residents, zip codes have an average population of 7,500 (USA.com, 2014), census tracts have an average of about 4,000 people, census block groups have about 1,500 people, and census blocks have as few as 600 people (STS, 2013)—although great variation in population size exists among all these groupings. Other geographic units not linked to the census bureau definitions can also be formed—such as the health care utilization-defined primary care service areas (each of which has about 17,000 individuals) (Goodman et al., 2003)—depending on the questions of interest.

The addition of environmental factors and community resources to the EHR to enable a more comprehensive understanding of the social and environmental determinants of health and the resources available to patients for implementation of health care treatments does not require any new information to be recorded in the EHR. Patient address is the only field required for the geocoding, and this information is part of every EHR. This makes inclusion of the CIS in the EHR highly feasible from the perspective of health care professionals. Health systems, however, must implement the linking procedures and must develop relationships with community stakeholder organizations that manage CISs. Limitations that make the linkage challenging include the lack of defined standards for reference data or methods for geocoding; the availability in each community of a CIS to which EHR data can be linked; the lack of technical expertise for EHR-CIS linkage; and maintenance of patient privacy during the linkage process.

A few examples of EHR-CIS linkages are available in the literature. For example, Comer and colleagues merged the Indiana Network for Patient Care, a large EHR system that aggregates data across institutions in a health information exchange (HIE), with the SAVI Community Information System (Comer et al., 2011). The EHR/HIE system was established 30 years ago and aggregates more than 200 data sources, including 80 emergency departments, 35 hospitals, more than 100 clinics, health departments, and ancillary data sources. The SAVI CIS collects, geocodes, organizes, and integrates data from more than 30 federal, state, and local providers: for example, departments of human services, welfare, education, housing, and health; public safety; and community and health facilities (Comer et al., 2011). Such a comprehensive linkage of EHRs and CISs within the same community is uncommon, however.

Environmental Exposures

Social determinants such as education level, poverty, race, ethnicity, housing, social context, social capital, and social connectedness are strongly associated with exposure to environmental hazards. For the purposes of this report, the committee focused on hazards introduced into the environment that cause adverse effects on human health, and concentrated on those hazards and conditions caused by or worsened by exposure that might lend themselves to a clinical intervention. In addition, the committee also concentrated on the clinician's ability to use information on a patient's social situation that may be used to improve a patient's situation. (See, for example, "The Case of Veronica" in Chapter 1, Box 1-1.)

Environmental exposures to hazards, such as pollutants and contaminants, come in many forms: chemical substances, allergens, noise, heat, light, and energy. Some are made by humans, and some are naturally occurring. Exposure to environmental toxicants can occur through one's occupation, in one's home, and in one's daily environment. A vast literature exists on the effects of specific contaminants and their effects on human health. For the most part, that literature is specific to the agent, with research conclusions pointing to the need for additional research, the inadequacy of animal models that limit inferences about the dose–response in humans, or limitations in epidemiological studies addressing threshold limits for exposure effects.

Evidence of Association with Health

Curtis et al. (2006) summarized research on a range of health effects of outdoor air pollution, including particulates, carbon monoxide, sulfur and nitrogen oxides, acid gases, metals, volatile organic compounds, solvents, pesticides, radiation, and bioaerosols. The general finding is that air pollution is associated with increased medical expense, morbidity, and premature mortality. The 2005 World Health Organization (WHO) air quality guidelines represent a widely agreed upon assessment of the health effects of air pollution (WHO, 2005).

Chronic exposure to air pollutants is a risk factor for the development of respiratory and cardiovascular disease. When solid fuel is used indoors, for example, it is the air pollutants produced by the solid fuel that is a risk factor for coronary obstructive pulmonary disease and lung cancer (WHO, 2011). According to the WHO guidelines, current scientific evidence has not yielded specific thresholds for the elimination of adverse human health effects resulting from particulate matter. Pope and Dockery (2006) reviewed the research literature on particulate matter covering almost a decade (1997 to 2006) and concluded that there is emerging evidence of particulate-matter-related cardiovascular health effects.

The WHO and the U.S. Environmental Protection Agency have set limits for ozone, which at ground level is a major constituent of photochemical smog. Excessive exposure to ozone can trigger breathing problems and asthma and reduce lung function. European studies report that daily mortality increases by 0.3 percent for an increase in ozone exposure of 10 micrograms per cubic meter ($\mu g/m^3$) (WHO, 2011).

Kampa and Castanas (2008, p. 362) have summarized this literature and conclude that "air pollution has both acute and chronic effects on human health, affecting a number of different systems and organs." In summarizing the effects of air pollution on children, Schwartz (2004) notes that recent research suggests an association between air pollution and infant mortality and an association between air pollution and the development of asthma. Schwartz (2004) also indicates that the evidence for the overall negative effects of air pollution on children has been growing.

Research evidence also supports a relationship between environmental allergens as a cause for primary care visits. In a study of the association between air pollution and primary care visits and consultations, Hajat et al. (2001) demonstrated that air pollution worsens allergic rhinitis, which leads to increased numbers of visits for medical care. Arbes et al. (2003) estimated the prevalence of dust mite allergens in beds and predictors of dust mite concentrations. That study found that most U.S. homes have detectable limits of dust mite allergens at levels associated with allergic sensitization and asthma. Using cross-sectional data from the 2005 Behavioral Risk Factor Surveillance System, Wen et al. (2009) found that alerts of poor air quality in the news media were significantly related to more changes in outdoor activities among people in whom asthma has been diagnosed than among others.

Cagney and Browning (2004) investigated the relationship between asthma and neighborhood factors associated with breathing problems. Their research indicated that measures of neighborhood context, such as physical and social decay and social trust, may be underlying factors associated with asthma. Research links asthma to social adversity brought on by environmental factors and disparities in population health (Rauh et al., 2008). Canino et al. (2009) noted that disparities in the incidence of asthma result from multiple, complex, and interrelated sources. The authors posit that clinical settings should routinely assess patient beliefs and financial barriers to disease management and that health care providers should receive enhanced cultural competence training to improve their communications with patients, especially for those whose diseases relate to complex environmental factors.

Usefulness

The committee did not find literature relating to how exposure information may be systematically reflected in medical records through the use of specific standards. No environmental agents per se are a part of Meaningful Use Stage 1 or 2. The *International Classification of Disease, 10th Revision, Clinical Modification* (WHO, 2013) is currently used to code diagnoses, findings, and so forth in EHRs. It contains major sections that deal with various external causes, such as:

- poisoning by drugs (T36–T50) and nonmedicinal substances, many of which are environmental hazards (T51–T65);
- transportation-related injuries (V00–V99);
- injuries related to falls (W00–W19); and
- injuries from mechanical forces (e.g., struck by falling tree) (W20–W49).

Consequently, diagnostic coding data for environmental hazards can be found in EHRs and can be related to other variables for research purposes. Exposure to select environmental agents, such as lead, is also mandated for reporting to public health agencies and, consequently, is included in electronic laboratory reporting. Laboratory test results can also be found in EHRs.

Health care providers are confronted with a wide spectrum of conditions that may have an environmental element that either causes or exacerbates a patient's condition. Many of the guidelines for environmental control exist for use at the population level but are not directly applicable to the patient. Much of the environmental research on social factors is not definitive as to cause and effect, nor does the research offer specific recommendations that clinicians may use in advising patients. Residence location may be the single strongest data item that can prove useful for research efforts to relate disease to social factors.

Availability of Nutritious Food Options

Within the context of communities, the availability of nutritious food options refers to the geospatial distribution of grocery stores, food vendors generally located in small stores, and restaurants. It can refer to overall food availability or, more specifically, to access to specific types of food, such as fruits and vegetables, sweetened beverages, calorie-dense foods, and fast foods. The concept of "food deserts" is a component of the broader construct of nutritious food options and refers to communities that have limited access to affordable and nutritious foods (IOM and NRC, 2009). Section 7527 of the 2008 Farm Bill defined a "food desert" as "an area in the United States with limited access to affordable and nutritious food, particularly such an area composed of predominantly lower-income neighborhoods and communities."

The availability of nutritious food is just one factor that determines food choices; the relative cost of food options, cultural factors, and taste preferences are additional influences. Although no uniform consensus on the meaning of available nutritious food options exists, most would agree that it includes proximity of food options, price, and travel time—the amount of time required to travel to purchase food.

Evidence on Association with Health

The hypothesized link between food options in the community and health is that the greater availability of nutritious food will increase the intake of healthful foods, such as fruits, vegetables, and whole grains, while lower availability of sweetened beverages will reduce the risk of obesity. The evidence, however, is mixed. Extant studies suggest that just an increase in fruit and vegetable intake without management of total calories is not associated with a reduced risk of obesity. The evidence of a lower risk of obesity and diabetes in association with the decreased intake of sweetened beverages is stronger (Schulze et al., 2004), but linking consumption to availability in neighborhoods has not been established. Ecological studies have found associations between a lack of availability of nutritious food options and obesity and diet-related chronic conditions (IOM and NRC, 2009). At the zip code level, the presence of supermarkets was associated with a lower risk of obesity (see, for example, Lopez-Zetina et al., 2006); particularly in urban areas (Michimi and Wimberly, 2010); whereas high density of small convenience stores was associated with an increased risk of obesity (Gibson, 2011; Wang et al., 2007). However, negative findings have also been reported between the food environment and obesity (Lee, 2012; Sturm and Ruopeng, 2014).

Usefulness

Obesity has become one of the top public health problems affecting the nation. Strategies to lower its incidence and mitigate its impact will need to take a holistic view and involve the entire health system rather than a sector-specific approach that involves only public health, education, behavioral change, or medical care. The distribution of obesity in the U.S.

population is not random, with a much greater risk being seen for lower-income individuals in urban and rural settings. The nutrition environment that individuals are exposed to is one factor in obesity risk.

Building a comprehensive data system that bridges community data with personal health data can provide the type of infrastructure needed for the IOM's vision of a systems approach to combating the obesity epidemic (IOM, 2012). Because linkage of EHR data with CIS data requires no new data entry for clinicians, the major feasibility issues to consider are costs and technical details of data linkage as well as the availability of information in CISs. The Philadelphia Department of Health, for example, has compiled a rich database on the locations of nutritious food options throughout the city of Philadelphia and has developed programs to reduce the amount of salt in Chinese restaurants and increase the amount of fruit and vegetables sold in corner stores (The Food Trust, 2012; Get Healthy Philly, 2013).

Transportation, Parks, and Open Spaces

The design and distribution of the parks, streets, open spaces, homes, schools, other buildings, roads, and walkways in a community constitute its built environment. In broad terms, the built environment is defined "to include land use patterns, the transportation system, and design features that together provide opportunities for travel and physical activity" (TRB and IOM, 2005, p. iii). It can be studied at several geographic levels, from the neighborhood level to the community and county levels. The built environment is a wonderful example of the ingenuity and creativity of humans, but because individuals spend nearly all of their time in it, it has both positive and negative effects on health. For children, the availability of parks and recreational facilities provides opportunities for exercise and prosocial development with friends during unstructured play time (Tester and Baker, 2009). These resources are less available in lower-income neighborhoods, an inequality that contributes to the risk of obesity among the children living there (Gordon-Larsen et al., 2006).

Evidence on Association with Health

Green neighborhoods facilitate physical activity and have also been linked to better physical and mental health (Astell-Burt et al., 2013a,b; Maas et al., 2006, 2009). These connections are just beginning to be understood; understanding the roles that individual, social, and built environmental factors have on physical activity is an emerging area of inquiry. What is now known is that physical activity levels have been decreasing over the past several decades as the amount of work required for activities of daily living has been minimized. Household chores, jobs, and getting to and from schools and the workplace are less energy intensive today than they were in previous decades. These trends, coupled with increased sedentary behavior during leisure time, have conspired to lower physical activity levels (IOM, 2005; TRB and IOM, 2005). Less clear is how specific changes in the built environment lead to predictable decrements in physical activity, although specific environmental variables such as access to recreation facilities, living in neighborhoods where others exercise, and the presence of enjoyable scenery have been positively associated with physical activity in several studies (Trost et al., 2010). Other attributes of the built environment associated with physical activity are mixed land use, well-connected street networks, more bikeways, and high residential density (Cavill, 2007; HSFC, 2007; Laxer and Janssen, 2013).

Further, people who use public transit get more exercise than drivers (Rissel et al., 2012; Wen and Rissel, 2008). Long commutes decrease physical activity and increase the risk of obesity (Brownson et al., 2005; Lopez-Zetina et al., 2006), and they are associated with less civic engagement (Choi et al., 2013).

Usefulness

If health care providers have information on their patients' built environment (e.g., urban design, land use), they can potentially use this information to describe treatment options for their patients and develop coordinated care with other health care providers or systems of care. Neighborhood indicators of access to recreational facilities and walking environments can be used to counsel patients on behavioral change and disease management. For example, patient-centered medical homes (PCMHs) are required to link patients with community health care and social service resources as one of their eight core functions (Wagner et al., 2012). A PCMH could leverage community resources by creating a merged EHR-community resources database that can generate a personalized set of recommendations for available local community resources. Research is needed to evaluate the practicability and usefulness of this information.

If the health system has information on its populations' built environment, it can use the information to tailor and target strategies and interventions. For example, the health system can identify areas where concentrations of the patient populations lack access to open spaces. Policies could be developed to create green spaces allowing for easier access to run or play. The availability of environmental information would also allow monitoring of trends in these factors over time across geographic areas. Building a comprehensive data system that bridges community data with personal health data can provide the type of infrastructure needed for the

IOM's vision of a systems approach to combating major health problems in the United States, such as the obesity epidemic (IOM, 2012).

If researchers have information on individuals' environmental attributes, they can perform population research on the causal impacts of changes in these environmental attributes on behaviors and on health outcomes. Longitudinal data on patients derived from their EHRs would be especially valuable in the establishment of causality. The availability of these data would enhance clinical research on determining to what extent environmental factors are useful in improving the outcomes of care for patients with conditions such as hypertension and diabetes.

Health Care and Social Services

The distribution of health care and social service agencies within a community is an important determinant of a population's access to these services. Assuming that the location of each agency is geocoded in a CIS, the distance between each agency and a patient's residence can be readily computed. The geographic distribution of health care resources has been termed "geographic accessibility" (Forrest and Starfield, 1998). While related to use in most studies, it is a weaker influence on use than financial accessibility. In virtually all countries without central personnel planning, health care resources are inequitably distributed, with more physicians located in more affluent communities (Matsumoto et al., 2010).

Evidence on Association with Health

For primary health care, the presence of fewer physicians in a locale has been shown to translate into poorer health outcomes (Starfield et al., 2005) at the state and county levels. Very little evidence to date suggests that better integration of community resources in a CIS with patient receipt of care improves outcomes (Stellefson et al., 2013).

Usefulness

PCMHs are required to link patients with community-based health care and social service resources. This is one of the eight core functions of PCMHs (Wagner et al., 2012). One vision of how the PCMH could leverage community resources is through the creation of a merged EHR-community resources database that enables the creation of a personalized set of recommendations of local community resources for each patient that is based on his or her health needs and that can be provided to the patient during a medical encounter.

Educational and Job Opportunities

Education, employment, and income generated from work are important socioeconomic determinants of individual and population health, and these are influenced by the educational and job opportunities available to members of a community. Educational opportunities can be measured by the availability of high-quality schools. Indeed, the quality and location of schools are some of the more important influences on the desirability of a neighborhood to families. Job prospects affect the employment rate and affluence of a community, and community unemployment rates would be a measure of this concept.

Evidence on Association with Health

The biomedical literature is devoid of evidence on how the distribution of educational opportunities relates to health. It is likely that these variables are more prominent in the social science literature, where the outcomes may be socioeconomic variables. Ample evidence suggests, however, that unemployment is associated with health, specifically all-cause mortality (Roelfs et al., 2011), suicide (Milner et al., 2013), and poorer mental health (Dooley et al., 1996; Puig-Barrachina et al., 2011).

Usefulness

Educational opportunities are distal to the causal pathway between socioeconomic status and health. They are better thought of as ecological determinants of a community's socioeconomic status. As such, they are unlikely to be of immediate interest or use to health care professionals but would be of interest to urban planners and public policy makers. Merely knowing the prevalence of job opportunities in a community is probably of less importance than knowing the unemployment trends and their downstream effects on psychological health and mortality.

Conclusion

Evidence of association between the neighborhood and community (geocodable) domains show that there are associations with health; further research to understand the validity and usefulness of these domains is currently being conducted. In some instances these domains are interrelated with candidate domains (e.g., availability of nutritious food options is interrelated with financial resource strain and dietary food patterns). (See Chapter 3 for more information on these candidate domains.) In other instances, these domains are already being captured in an electronic system (e.g., ICD codes and public health surveillance systems). Currently, these domains are not routinely available in a standardized format; thus, in its deliberation for this domain, the committee also considered the volume of work required and complexities to capture geocodable domains. For these reasons, the committee elected not to select environmental pollution and neighborhood resources (availability of nutritious food options; transportation, parks, and open spaces; health care and social services; and educational and job opportunities) as candidate domains.

The committee noted that with the collection of a geocodable residential address, a wide variety of exposures can be explored. Some reflect compositional characteristics of the neighborhood, and others reflect contextual characteristics, including hazards and resources in the physical and social environment. The committee opted to focus on aspects of composition and did not identify any contextual domains at this time. If health care providers collect a geocodable address in their EHRs, they may choose to use it to import data relevant to their community and population. The committee hopes that in the future these variables will be routinely standardized and thus able to be linked to all patient records.

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Privacy Concerns Related to Inclusion of Social and Behavioral Determinants of Health in Electronic Health Records

Deven McGraw[1]

SUMMARY

The Institute of Medicine Committee on the Recommended Social and Behavioral Domains and Measures for Electronic Health Records has been tasked with identifying 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). In its initial report, the committee has identified a candidate set of domains for consideration for inclusion in EHRs (IOM, 2014). This paper addresses privacy concerns related to the inclusion of social and behavioral determinants of health (SBDH) in EHRs. This paper discusses the purpose of assuring appropriate privacy protections for this information, summarizes the federal privacy and security laws that govern this information and the technical capability of certified EHR technology (CEHRT) to reinforce the privacy protections afforded to this information, and provides some additional recommendations to assure public trust in the collection, use and disclosure of SBDH information.

In summary, eligible professionals and hospitals participating in the Meaningful Use program will want the trust of patients in collecting, using and sharing SBDH data, and compliance with applicable law is an essential first step toward gaining this trust. Eligible professionals and hospitals will need to comply with the Health Insurance Portability and Accountability Act of 1996 (HIPAA) privacy and security rules with respect to this infor-

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[1] Center for Democracy and Technology.

mation; other federal laws, such as the rules protecting identifiable data coming from most substance abuse treatment programs, may also apply. The professional or hospital may need to comply with state law with respect to the collection, use, and disclosure of this information; an examination of potentially applicable state laws is beyond the scope of this paper.

HIPAA allows SBDH information to be collected by health care providers where the information is reasonably necessary to accomplish the purposes for which it is collected. HIPAA also allows SBDH information to then be used and disclosed for individual treatment purposes without the need to first obtain the oral consent or written authorization of the individual. Disclosures to public health authorities acting within the scope of their authority may also be made without the need to obtain consent or authorization. However, disclosures to other state and local authorities, or uses and disclosures for purposes not related to treatment of the patient (or payment for that care) may require the patient's prior express authorization. Professionals and hospitals are required to abide by laws requiring specific patient authorization prior to disclosure; however, most certified EHR technology (CEHRT) today does not have the capability to segment data requiring authorization from data that may be shared without the need to obtain authorization.

Notwithstanding the ability under law to collect, use, and share SBDH information for treatment purposes, eligible professionals and hospitals may still want to take additional steps—above and beyond what the law requires—to provide assurances to patients. Such steps could include assuring greater transparency to patients about uses and disclosures of this information; providing patients with some choices about the collection and sharing of this information (such as through verbal consent or opting-out); and adopting role-based access controls. However, the capability of CEHRT to deploy additional protections for this data within the EHR is uncertain.

WHY PRIVACY MATTERS

The ethical foundation for keeping patient information confidential dates back to the Hippocratic Oath. A 2013 survey of consumer attitudes toward health information technology and health information exchange found a high percentage of public support for EHRs, but 50 percent of respondents (all of whom had experience with doctors using EHRs) thought EHRs would worsen privacy and security (Ancker et al., 2013). These results essentially reaffirmed previous surveys conducted between 2010–2012 on health information technology or EHRs and privacy concerns. The consequences for failing to address privacy and security concerns could be significant for some patients: one out of eight patients does not seek treatment for a sensitive medical condition, or withholds critical information from health care providers, because of concerns about confidentiality (Agaku et al., 2013).

Do certain segments of the population care more—or less—about health privacy? A thorough review of the research in this area is beyond the scope of this paper. In a 2005 survey of attitudes toward health information technology and privacy, the California HealthCare Foundation found people with chronic illnesses and racial and ethnic minorities reported even higher levels of concern about the privacy of their medical records and were more likely than average to withhold information for fear of its being improperly used (California HealthCare Foundation, 2005). The 2013 survey cited above found no distinction in privacy concerns based on sociodemographic variables; however, the sample for the survey likely underrepresented minorities, particularly Hispanics. Surveys of privacy concerns and use of the Internet typically do not focus on health information but may provide some indication of public attitudes toward privacy and digital technologies that could be instructive. A recent Pew Research Center study found that persons ages 30–49 were most often eager to try to control access to their personal information (such as by using encryption or deleting cookies), and low-income Internet users were more likely to report negative experiences with Internet use, such as having an email or social media account compromised, having their reputation damaged by online activity, or being stalked or harassed online (Rainie et al., 2003).

The information included in the candidate domains identified by the committee in the initial report may be highly sensitive to some individuals. For example, patients may worry that information about alcohol use, if shared outside of the treatment setting, may be used to affect their employment status or affect their ability to obtain a loan. Patients may be concerned about being treated differently because professional and hospital staff sees information about food or housing insecurity, socioeconomic characteristics, or exposure to violence. Particularly in smaller towns, where the local hospital may be one of the largest employers, patients may be concerned about socioeconomic or behavioral information being seen by friends, co-workers or neighbors. Such information is of the type that patients may not expect to have collected and stored in their doctor's or their hospital's medical record.

If the conditions for receipt of Meaningful Use incentive payments either require or encourage the collection of this information, eligible professionals and hospitals will need to take care to comply with any applicable privacy and security laws and ideally adopt organizational or institutional good data stewardship practices to earn (and keep) patient trust in the collection, use, and disclosure of this information. This paper discusses the applicable federal laws that could apply to the collection, use, and disclosure of SBDH information, as well as additional considerations that may help build trust in having this information be part of treatment, care coordination, and population health activities.

THE HIPAA PRIVACY AND SECURITY RULES

Eligible professionals and eligible hospitals meet the definition of "covered entity" under HIPAA,[2] and therefore are required to comply with the HIPAA privacy and security regulations, known as the Privacy Rule and the Security Rule. The Privacy Rule establishes the rules governing the use and disclosure of identifiable health information in either paper or electronic format (otherwise known as protected health information or PHI) by covered entities; the Security Rule establishes the security safeguards to be adopted to protect electronic identifiable health information (otherwise known as ePHI). (The Privacy Rule requires entities to adopt reasonable security safeguards for paper records.[3])

The definition of PHI is broad and includes SBDH data collected by a covered entity. Health information "relates to the past, present, or future physical or mental health or condition of an individual; *the provision of health care to an individual*"; or payment for care (emphasis added).[4] Health care "means care, services or supplies *related to* the health of an individual."[5] It includes, "but is not limited to, preventive, diagnostic, therapeutic, rehabilitative, maintenance or palliative care, counseling service, assessment or procedure [with regard to] the physical or mental condition, or functional status, of an individual or that affects the structure or function of the body."[6] When health information is identifiable to a patient, as long as it is not specifically exempt from coverage under HIPAA (which would not be the case for identifiable information collected by eligible professionals and eligible hospitals), it is PHI and governed by HIPAA. SBDH information falls within HIPAA's definition of health care, and because it will initially be collected to inform treatment decisions, there is no doubt it is PHI.

COLLECTION OF SBDH INFORMATION

HIPAA's Privacy Rule does not require providers to get the patient's oral consent or written authorization before collecting PHI. However,

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[2] 45 CFR 160.103.

[3] 45 CFR 164.530(c).

[4] 45 CFR 160.103.

[5] Id.

[6] Id.

the HIPAA Privacy Rule's "minimum necessary" provisions do set some parameters with respect to "requests" for PHI.[7] When information is being requested from another covered entity (for example, from another health care provider), the "minimum necessary" provisions require the request to be limited to that which is "reasonably necessary to accomplish the purpose for which the request is made."[8] With respect to requests for PHI that are made on a routine or recurring basis, a provider must implement policies and procedures that limit the PHI requested to that which is reasonably necessary to fulfill the purpose for the request.[9] For other requests—those not made of other covered entities or that do not occur on a routine basis—the provider is required to develop criteria that will enable requests to be limited to what is reasonably necessary to accomplish the purpose and review individual requests in accordance with those criteria.[10] "Minimum necessary" standard: "when using or disclosing [PHI], or when requesting [PHI] from another covered entity, a covered entity must make reasonable efforts to limit [PHI] to the minimum necessary to accomplish the intended purpose of the use, disclosure, or request." With respect to the collection of SBDH data by eligible professionals and hospitals as part of the Meaningful Use program, these rules mean that providers will need to develop policies and protocols for routine receipt of data (for example, through direct feeds from social service agencies or through protocols for patient interviews) to assure that the information collected is what is reasonably necessary to fulfill the purpose (or purposes) for which it is collected. Where the collection is not routine but more episodic, there is still a requirement to develop criteria to be applied to individual requests to assure that collection meets the "reasonably necessary" standard.

Note in the case of information that is collected directly (or even automatically) by the provider from another source, such as a social service agency, that there may be rules governing the ability of the other source of this information to release it. For example, the Privacy Act of 1974 generally prohibits federal agencies from releasing personal information about individuals without their authorization, with some exceptions,[11] and states frequently have their own versions of privacy laws that restrict the ability of state agencies to release personal information.[12] The governor of the Commonwealth of Massachusetts recently came under criticism for upholding privacy laws and failing to release information regarding whether the

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[7] 45 CFR 164.514(d)(1).

[8] 45 CFR 164.514(d)(4)(i).

[9] 45 CFR 164.514(d)(4)(ii).

[10] 45 CFR 164.514(d)(4)(iii).

[11] 5 U.S.C. § 552a.

[12] See, for example, the California Information Practices Act of 1977, Civil Code Section 1798.

person accused of setting off bombs in the crowd watching the Boston Marathon received state benefits (Post Staff Report, 2013).

USES AND DISCLOSURES FOR TREATMENT, OPERATIONS, AND PAYMENT

The Privacy Rule includes provisions governing the use and disclosure of SBDH information and treats it the same as other information gathered by a professional and stored in the records (with the exception of psychotherapy notes—see below). Eligible professionals and hospitals may use and disclose this information, along with other information gathered from the patient, to treat the patient, and for treatment-related administrative tasks (known as health care operations), without needing to first obtain the oral consent or written authorization of the patient.[13] Health care operations includes (but is not limited to) "population-based activities relating to improving health or reducing health care costs, . . . case management and care coordination, contacting [professionals] and patients with information about treatment alternatives, and related functions that do not include treatment."[14]

Professionals and hospitals may also disclose this information, without the need for prior consent or authorization, for purposes of obtaining payment for care. All uses and disclosures of PHI (except disclosures for treatment purposes) are subject to the Privacy Rule's aforementioned "minimum necessary" standard: "when using or disclosing [PHI], a covered entity must make reasonable efforts to limit [PHI] to the minimum necessary to accomplish the intended purpose of the use [or] disclosure."[15] This standard requires a covered entity to identify the persons or classes of persons who need access to PHI to carry out their duties, and the category or categories of PHI to which access is needed—and then make reasonable efforts to limit PHI access according to those decisions.[16] Although the U.S. Department of Health and Human Services' Office for Civil Rights, which enforces HIPAA, has issued little guidance on implementation of the minimum necessary standard, these provisions arguably would obligate covered

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[13] 45 CFR 164.502(a)(1)(ii). Treatment is "the provision, coordination, or management of health care and related services by one or more health care providers," including coordinating or managing health care with a third party. 45 CFR 164.501.

[14] 45 CFR 164.501.

[15] 45 CFR 164.502(b)(1).

[16] 45 CFR 164.514(d)(2).

entities to take reasonable steps to limit access to SBDH data to workforce members with a need to know.[17]

A covered entity is permitted to rely, "if such reliance is reasonable under the circumstances," on a requested disclosure of PHI as meeting the standards for minimum necessary if it is disclosing information for public health purposes if the public health authority represents that the information requested is the minimum necessary for the stated purpose.[18] The HIPAA Privacy Rule also allows professionals and hospitals to rely on the information requests from another covered entity, such as a payer, for what constitutes minimum necessary.[19] Consequently, if a payer does not request or require the information, professionals and hospitals will need to consider whether disclosing SBDH data is necessary to support payment. The Privacy Rule's minimum necessary provisions also prohibit the disclosure of an entire medical record, except when the entire record is specifically justified as the amount reasonably necessary to accomplish the purpose of the use, disclosure, or request.[20] These provisions arguably require professionals and hospitals to have a way to prevent access to or disclosure of certain types of data in the EHR, including SBDH, if such data is not needed to accomplish a given purpose; however, as noted later in the report, it is not clear that certified EHRs can accomplish segmentation of this data.

As noted above, psychotherapy notes are treated differently under the Privacy Rule. Psychotherapy notes are "recorded (in any medium) by a health care provider who is a mental health professional documenting or analyzing the contents of conversation during a private counseling session or a group, joint or family counseling session and are separated from the rest of the individual's medical record."[21] A covered entity is required to obtain the patient's express written authorization for any use or disclosure of psychotherapy notes, except for the following:

- The treatment uses by the originator of the notes;
- Use or disclosure in mental health professional training programs;
- Use by the covered entity to defend itself in a lawsuit brought by the individual who is the subject of the notes;
- Disclosures required by law;
- Uses related to oversight of the originator of the notes;

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[17] Of note, HITECH requires HHS to issue guidance on the minimum necessary standard. See Section 13405(b)(1)(B) of the Health Information Technology for Economic and Clinical Health Act. As of the writing of this report, the guidance had not been issued.

[18] 45 CFR 164.514(d)(3)(iii)(A).

[19] 45 CFR 164.514(d)(3)(iii)(B).

[20] 45 CFR 164.514(d)(5).

[21] 45 CFR 164.502.

- Disclosures to coroners and examiners to help determine cause of death; and
- Disclosures to prevent an imminent threat to health or safety.[22]

Consequently, SBDH data collected by a mental health professional in psychotherapy notes would enjoy greater protection but be less available for use in treatment by other professionals.

Disclosures to Public Health Authorities

The Privacy Rule permits the disclosure of PHI to public health authorities "authorized by law to collect or receive such information for the purpose of preventing or controlling disease, injury, or disability."[23] A public health authority is an agency or authority of the United States, a state or territory (or a political subdivision thereof), or an Indian tribe, "or a person or entity acting under grant of authority from or under contract with such public agency … that is responsible for public health matters as part of its official mandate."[24] Consequently, an eligible professional or hospital may disclose SBDH data to a public health authority, as long as that public health authority has legal authorization to collect (either on the initiative of the public health authority or as initiated by the professional or hospital) that data. Such a disclosure does not require the prior consent or authorization of the individual, although the eligible providers or eligible hospitals may need to inform the patient of this disclosure if that patient requests an "accounting" of disclosures from the record.[25] Such disclosures would also be covered by the Privacy Rule's minimum necessary provisions; however, the eligible professional or eligible hospital can rely on the public health authority's reasonable determinations of what constitutes the minimum necessary amount of data required to be shared with the authority.

Disclosures to Other Authorities (Not Public Health)

Eligible professionals and hospitals may have a need (or face a legal requirement) to disclose SBDH data from their records to other, nonpublic health authorities. Not all governmental authorities will fall under the definition of a "public health" authority; for example, an agency whose purpose is to connect individuals with other social services, like income

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[22] 45 CFR 164.508(a)(2).

[23] 45 CFR 164.512(b).

[24] 45 CFR 164.501.

[25] 45 CFR 164.528. The report is required to account for the past 6 years of disclosures required to be covered. Although this has not been formally studied, anecdotally these reports are rare requested by patients. See Health IT Policy Committee (2013).

or food and nutrition assistance, would likely not be considered a public health authority.[26]

The Privacy Rule does permit disclosures of PHI by eligible professionals and hospitals where they are required to do so by law.[27] For example, if a state has a law requiring the disclosure of SBDH data to a particular agency, an eligible professional or hospital can make that disclosure without running afoul of HIPAA. The Privacy Rule also permits professionals and hospitals to disclose PHI:

- To public health or other authorities "authorized by law to receive reports of child abuse or neglect";
- To report abuse, neglect, or domestic violence to an entity authorized by law to receive such reports;
- To certain entities or individuals for workplace safety matters; and
- To avert a serious and imminent threat to health or safety.[28]

Note that these are permitted, and not required, disclosures under HIPAA. In the absence of another law or professional obligation to disclose this information, an eligible professional or hospital is not required to disclose SBDH or any other type of PHI for these purposes. These disclosures also are subject to HIPAA's minimum necessary standard.

HIPAA also permits PHI to be disclosed for law enforcement purposes—but there are limits to the amount of information that can be disclosed when the disclosure is not being conducted pursuant to a subpoena or other court order.[29] For example, an eligible professional or hospital may disclose limited information to assist in the identification or location of a suspect, fugitive, or material witness or missing person.[30] The information that may be disclosed is limited to name and address, date and place of birth, social security number, ABO blood type and Rh factor, type of injury, date and time of treatment, date and time of death (if applicable), and a description of distinguishing facial characteristics[31]—in other words,

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[26] There is no definitive guidance on the breadth of the definition of a public health authority, and the definition of "health care" under HIPAA is broad, as noted earlier in this paper. However, other provisions of the Privacy Rule contemplate the sharing by health insurers of information with "other government benefit programs," which suggests the regulators did not intend for all government benefits with a nexus to health to fall within the definition of a "public health" authority. See 45 CFR 164.512(k)(6).

[27] 45 CFR 164.512(a).

[28] 45 CFR 164.512(b), (c), and (j).

[29] 45 CFR 164.512(f).

[30] 45 CFR 164.512(f)(2).

[31] 45 CFR 164.512(f)(2)(i).

largely not SBDH data in the domains identified in the committee's draft report.

Uses and Disclosures Requiring Authorization: Research

Under the Privacy Rule, a use or disclosure of PHI—including SBDH information—that is not expressly permitted by the Privacy Rule requires the prior authorization of the patient. For example, if an eligible professional or hospital wants to voluntarily share identifiable SBDH data with a nonpublic health social service agency, they would need the prior authorization of the patient. To be valid, an authorization required by HIPAA must be in writing and include

- A description of the information to be used or disclosed;
- The name of the person or class of persons authorized to make the requested disclosure;
- The name of the person or class of persons to whom the information is to be disclosed;
- A description of each purpose of the disclosure;
- An expiration date or event; and
- The signature of the individual or their legal personal representative.[32]

Uses and disclosures of identifiable SBDH data for research purposes require prior patient authorization—but there are exceptions to this rule.[33] For example, uses of this information in preparation for research (for example, to identify potential subjects who might be approached about involvement in a research study) does not require prior patient authorization, as long as the information is not removed from covered entity.[34] In addition, a privacy board or institutional review board (IRB) may waive the requirement for authorization if it determines (and documents) that the use or disclosure of PHI involves no more than minimal risk to the privacy of the individuals based on, at the least, the presence of the following elements:

- An adequate plan to protect the identifiers from improper use and disclosure;
- An adequate plan to destroy the identifiers at the earliest opportunity consistent with the conduct of the research;

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[32] 45 CFR 164.508(c)(1).

[33] Research is a "systematic investigation, including research development, testing, and evaluation, designed to develop or contribute to generalizable knowledge." See 45 CFR 164.502.

[34] 45 CFR 164.512(i)(1)(ii).

- With a few exceptions, adequate written assurances that the PHI will not be reused or redisclosed to any other person or entity;
- The research could not practicably be conducted without the waiver; and
- The research could not practicably be conducted without access to the information.[35]

The Privacy Rule has historically required authorizations for research uses and disclosures of PHI to be study specific and not general in nature. However, recently the Office for Civil Rights issued guidance allowing patients to more generally authorize future research using their PHI, as long as the description of the future research uses is sufficient that the data subjects would reasonably expect their information to be used for that research.[36]

THE HIPAA SECURITY RULE

As noted above, the HIPAA Security Rule applies to electronic PHI (or ePHI),[37] and the Rule does not vary by the type of PHI—so SBDH data collected by eligible professionals and hospitals is subject to the same rules under HIPAA as apply to other types of PHI they collect. CEHRT includes functionalities that can assist them with compliance. For example, CEHRT is required to include capabilities for identity proofing and authentication of system users, access controls, automatic log-off, encryption of data at rest and in motion, and protections for data integrity.[38]

But the eligible professional or hospital cannot depend on their CEHRT to fulfill all of their Security Rule responsibilities, which include administrative, technical, and physical safeguards. Professionals and hospitals are required, both by the Security Rule as well as by the Meaningful Use requirements, to conduct a security risk assessment and address any security deficiencies (HITECH, 2014). They also must comply with all Security Rule requirements, and consider all "addressable" implementation specifications. Such specifications are not per se required but are also not optional. Covered entities are expected to implement addressable specifications unless they document the reasons why those specifications cannot be implemented and adopt an alternative measure that provides the same or similar safeguards.[39] For example, encryption of information while at rest

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[35] 45 CFR 154.512(i)(2).

[36] 78 Fed. Reg. 5566, 5612–13 (January 25, 2013).

[37] 45 CFR 164.302.

[38] 45 CFR 170.302, sections (O)–(V).

[39] 45 CFR 164.306(d)(3).

(in storage) is an addressable implementation specification. Consequently, encryption of data at rest is not absolutely required by the Security Rule, but the expectation is that it will be implemented unless the covered entity provides documentation for declining to implement encryption and adopting alternative safeguards instead.

Information That Is Not Easily Identifiable: De-Identified Data and Limited Datasets

The HIPAA Privacy and Security Rules apply only to information that is identifiable. Information that is "de-identified"—which is defined as information "with respect to which there is no reasonable basis to believe that the information can be used to identify an individual"[40]—is not subject to HIPAA, whether it is SBDH or another type of information. The Privacy Rule provides two methodologies for de-identifying health information: the safe harbor, which requires the removal of 18 categories of identifiers[41] and no actual knowledge that the data can be re-identified; and the expert or statistician method, which requires that a person with appropriate statistical experience determines and documents that the risk of re-identification, given the anticipated recipients of the data and the other information that might be reasonably available to them, is very small.[42] Note that under both methodologies, the standard is not zero risk of re-identification; consequently, some very low, residual risk is likely to exist even in a properly de-identified HIPAA dataset. Covered entities are not required to obtain commitments from de-identified data recipients not to re-identify this data, but they may decide to do so as a matter of practice.

The HIPAA Privacy Rule also allows covered entities to use a "limited dataset" for health care operations, public health, and research.[43] A limited dataset can be achieved by removing 16 categories of identifiers—essentially the safe harbor list for de-identification, but dates and some geographic information are allowed to be retained.[44] These data are considered to be PHI; unlike de-identified data, which is not regulated by HIPAA, covered entities may not use or disclose limited datasets without a data use agreement that establishes the permitted purposes for which the dataset may be used or disclosed and prohibits the re-identification of individual patients.[45] There are advantages to the use of limited datasets. For example, limited datasets may frequently meet the criteria for waiving the requirement for

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[40] 45 CFR 164.514(a).
[41] 45 CFR 164.514(b)(2).
[42] 45 CFR 164.514(b)(1).
[43] 45 CFR 164.514(e)(3).
[44] 45 CFR 164.514(e)(2).
[45] 45 CFR 164.514(e)(4).

authorization to use PHI for research purposes.[46] In addition, a limited dataset may be a way of achieving minimum necessary standards for health care operations, research, and public health disclosures.[47]

Other Laws Protecting the Privacy and Security of Health Information

Information that is collected by a federally funded or federally assisted substance abuse treatment provider, and that identifies or has the potential to identify the patient as someone receiving (or who has received) substance abuse treatment, is also governed by federal law—42 CFR Part 2 (otherwise known as Part 2). These rules allow information to be used by the actual Part 2 provider for treatment purposes—but disclosure of this information, even for treatment purposes, requires the express authorization of the patient, and this information cannot be redisclosed by the recipient without obtaining new authorization from the patient.[48] For example, if a substance abuse treatment provider refers a patient to an eligible professional or hospital, that substance abuse treatment provider would need to obtain authorization from the patient prior to sending identifiable information—such as SBDH data—to the professional or hospital. The substance abuse treatment provider is required to provide notice to the recipient that the information is subject to Part 2 and cannot be further disclosed without prior patient authorization.[49] Once the professional or hospital receives that data (with the patient's authorization), they can use it to treat the patient—but cannot further disclose it without additional patient authorization. If they do obtain this authorization, they are required to similarly provide notice to the recipient that this information cannot be redisclosed without authorization.

State laws also may provide additional protections for certain types of SBDH information. HIPAA does not preempt any state laws that provide greater privacy protections for patients.[50] As a result, many states have enacted laws providing greater protections for certain types of information—such as mental health or genomic data, or HIV test results. Often these laws require express consent or authorization from the patient before information can be disclosed. Eligible professionals and hospitals collecting SBDH will need to consider whether there are additional laws in their states governing how they collect, use, and disclose this information. (A more comprehensive examination of state law is beyond the scope of

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[46] 45 CFR 164.512(i)(2)(ii).

[47] Section 13405(b)(1)(A) of the Health Information Technology for Economic and Clinical Health Act.

[48] 42 CFR Part 2, Sections 2.13, 2.32.

[49] Id. Section 2.32.

[50] 45 CFR 160.203.

this paper.) Of note, states also often have laws providing greater protections to certain types of data about minors. For example, California allows minors to consent to receive certain types of medical care—such as sexual and reproductive health care—without the need to obtain the consent of a parent or guardian (Adolescent Health Working Group, 2002). In that case, the minor has the right to keep that information confidential, and the information cannot be disclosed to the parent or guardian (or sometimes to any others) without the express consent of the minor. HIPAA defers to state law on issues of minor consent and privacy.[51]

Other Non-Legal Considerations: Good Privacy Stewardship and the Limits of Technology

To the extent that some SBDH data are of the type that patients are not accustomed to sharing with their medical providers, and that may be highly sensitive to some patients, eligible professionals and hospitals may seek to treat this information with greater sensitivity, even though HIPAA and other applicable laws may treat it the same as any other health information. For example, information about financial resource strain, food and housing insecurity, social connections and social isolation, exposure to violence, and socioeconomic characteristics is not information patients are generally accustomed to having collected by their medical providers, and they may consider it to be sensitive.[52] HIPAA provides some parameters for how health care providers can collect, use, and disclose this information, but once the information is disclosed, even where done lawfully, the recipient may not be subject to HIPAA or other confidentiality standards.

Ultimately, the goal of protecting the privacy and confidentiality of this information is to earn the trust of the patients in its collection, use, and disclosure for important, legitimate purposes. Eligible professionals (EPs) and eligible hospitals (EHs) should consider the mantra often relied on by the federal Health IT Policy Committee: the patient should not be surprised to learn what happens to their health data. At a minimum, this suggests EPs and EHs should make efforts to be transparent to patients about collection, use, and disclosure of their health information and this may be particularly true for SBDH data that may raise heightened sensitivities. Such transparency does not have to be a lengthy disclosure form—even a conversation with the patient in a face-to-face, virtual, or telephone setting can be helpful. HIPAA requires covered entities to provide patients with

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[51] 45 CFR 164.502(g)(2).

[52] Note, however, that some have argued that special treatment for sensitive information perpetuates stigma. See, for example, Evans and Burke (2008) and Mills (2009).

a Notice of Privacy Practices[53]—but this notice is not required to focus on the details of what covered entities actually do with health information but instead explains what HIPAA permits and what types of uses and disclosures require authorization.[54] The notice historically has not been easily read or understood by patients (Houchhauser, 2003), although recent improvements to the model notice may result in increased reading and comprehension (HHS, 2014). But given the way this notice has historically been treated by patients, transparency efforts with respect to collection, use and disclosure of SBDH data should not be addressed by mere inclusion in the HIPAA-required Notice of Privacy Practices.

Often transparency goals can be met through an informed consent process. As noted above, HIPAA does not require the consent or authorization of the patient to share SBDH data for treatment purposes, or for public health or other legally required purposes—but an eligible professional or hospital may decide to obtain consent as a matter of practice. HIPAA expressly permits covered entities to do this,[55] and in the case where HIPAA does not require prior written authorization, entities may use other ways to inform and gather assent from the patient. For example, a provider may document that a patient has orally agreed to share SBDH information, or may adopt a policy of informing patients about the policies and practices with respect to the use and disclosure of SBDH data and allow patients with objections to opt out.[56] Note that if the right to opt out is provided, eligible professionals and hospitals should have the capability to honor decisions to opt out.

In general, access to information under HIPAA is for those with a need to have the information in order to perform their duties, and the minimum necessary rule—which applies to collection and use of PHI, and disclosures of PHI except for treatment purposes—reinforces the need to take precautions to reveal only relevant data to appropriate persons for lawful purposes. Under the HIPAA Security Rule, covered entities are required to implement procedures to control and validate a person's access based on their role or function,[57] but the Rule leaves discretion to covered entities about how to implement this. Eligible professionals and hospitals should consider the potential for access controls to assure only appropriate access to some of the more sensitive aspects of patient records, keeping in mind the technological capabilities (and potential limits) of their CEHRT.

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[53] 45 CFR 164.520(a).

[54] 45 CFR 164.520(b).

[55] 45 CFR 164.506(b).

[56] The HIPAA Privacy Rule does provide patients with a right to request that information not be used or disclosed; however, the Rule does not require providers to agree to this request. See 45 CFR 164.522(a).

[57] 45 CFR 164.310(a)(2)(iii).

The presence of laws providing special protections to certain types of data or with respect to certain types of uses or disclosures—and the desire to afford such protections even in the absence of legal requirements—has led to calls for technical capability within CEHRT to segment or sequester such sensitive information, so patients can make more granular choices with respect to data sharing (enabling them to allow sharing of less sensitive information and to withhold sensitive information, depending on the circumstances). However, the certification requirements for CEHRT do not require the inclusion of segmentation capabilities, and as a result, CEHRT used by eligible professionals and hospitals may not have the capability to honor commitments to patients with respect to granular consent. The Health IT Policy Committee, through its Privacy and Security Tiger Team, is currently considering the viability of technical capabilities to segment substance abuse treatment data covered under Part 2 that were initially piloted as part of the Standards and Interoperability Framework of the Office of the National Coordinator for Health IT (Bowman, 2014). Although this capability is being tested for use by providers covered by Part 2, and potentially the non–Part 2 providers to whom they customarily refer, it is technology that may be useful to provide additional protections to other types of sensitive data. But whether CEHRT will include this functionality in the future (either through a certification requirement or through voluntary inclusion of this capability) is unknown.

CONCLUSION

Eligible professionals and hospitals participating in the Meaningful Use program may, under HIPAA, collect, use, and share SBDH data for treatment purposes, and disclose this data to public health officials acting within the scope of their authority, without the need to first obtain the consent of the patient. Express patient authorization is required to share SBDH data for purposes such as research (unless the authorization requirement is waived by a Privacy Board or an IRB) and with other social service agencies. Professionals and hospitals will need to assure compliance with baseline federal (and potentially state) health privacy laws; however, building the trust of patients in the collection, use, and responsible sharing of this information is critical and may require the adoption of additional measures, such as transparency and consent (either opt in or opt out) and access controls. Eligible professionals and hospitals will need to determine whether such additional measures, when they are dependent on technology, can actually be accomplished by their CEHRT.

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C

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 **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**

11:30–12:30	**Presentation of the Charge to the Committee**
	Robert M. Kaplan, Ph.D. *Director of the Office of Behavioral and Social Sciences Research* *National Institutes of Health*
	William Riley, Ph.D. *Chief, Science of Research and Technology Branch* *Division of Cancer Control and Population Sciences* *National Cancer Institute, National Institutes of Health*
	Maureen Boyle, Ph.D. *Team Leader Health Information Technology* *Substance Abuse and Mental Health Services Administration*
	Robert Hahn, Ph.D., M.P.H. *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**

SECOND MEETING

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

8:30–8:40 **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

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**

THIRD MEETING

February 6, 2014
Beckman Center of the National Academy of Sciences
100 Academy Drive
Irvine, CA 92617

8:30–8:40 **Welcome and Overview**

Nancy E. Adler, Ph.D.
Committee Co-Chair

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

8:40–9:35 **Panel 1: Measurement Issues of Social and Behavioral Determinants of Health**

Richard Gershon, Ph.D.
Associate Professor, Northwestern University
Departments of Medical Social Sciences and
Preventive Medicine—Health and Biomedical Informatics

Paul Crane, M.D., M.P.H.
Affiliate Faculty, Group Health Research Institute
Associate Professor, University of Washington
Department of Medicine

Ron Hays, Ph.D.
Professor, UCLA Department of Health Policy and Management
Professor, UCLA Department of Medicine
Senior Behavioral Scientist, RAND

9:35–9:55 **Questions from the Committee Members**

9:55–10:50 **Panel 2: Implementation Issues of Social and Behavioral Determinants of Health in the EHR**

Paul Tang, M.D., M.S.
Vice President, Palo Alto Medical Foundation
Associate Professor, Stanford University Department of Medicine

Charlene Underwood, M.B.A.
Senior Director, Government and Industry Affairs for Siemens Medical Solutions

Neil Calman, M.D. (by phone)
President, Institute for Family Health
Chair, Mount Sinai School of Medicine, Department of Family Medicine and Community Health

10:50–11:10 **Questions from the Committee Members**

11:10–11:30	**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**

FOURTH MEETING

April 8, 2014
National Academy of Sciences Building
2101 Constitution Avenue, NW
Washington, DC 20418

8:30–8:40	**Welcome and Overview**
	Nancy E. Adler, Ph.D. *Committee Co-Chair*
	William W. Stead, M.D. *Committee Co-Chair*
8:40–9:00	**Presentation on *Capturing Social and Behavioral Domains for Electronic Health Records: Phase 1 Report***
	Nancy E. Adler, Ph.D. *Committee Co-Chair*
	William W. Stead, M.D. *Committee Co-Chair*
9:00–10:05	**Panel 1: Linking EHRs Between Public Health Departments, Social Service Agencies, and Other Relevant Organizations: How to Create Information Systems with Data That Flow Both Ways**
9:00–9:15	***Michael Buck, Ph.D.*** *NYC Department of Health and Mental Hygiene*

9:15–9:30 ***Art Davidson, M.D., M.S.P.H.***
Denver Public Health, Denver Health

9:30–9:45 ***William A. Yasnoff, M.D., Ph.D.***
National Health Information Infrastructure Advisors

9:45–10:05 **Questions from the Committee Members**

10:05–10:15 **Break**

10:15–11:40 **Panel 2: Obstacles in Adding Measures to EHRs and Ways to Overcome These for the Patient, Provider, System, and Society**

10:15–10:30 ***Shaun Grannis, M.D.***
The Regenstrief Institute, Indiana University School of Medicine

10:30–10:45 ***Karen Tirozzi, M.S.W.***
Health Leads

10:45–11:00 ***Abigail Sears, M.B.A., M.H.A.***
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11:00–11:15 ***Deven McGraw, J.D., M.P.H.***

11:15–11:40 **Questions from the Committee Members**

11:40–12:00 **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.*

12:00 **Adjourn**

D

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 & 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 his or her 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 the chief strategy officer and associate vice chancellor for health affairs 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 an M.A. in 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 of 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 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 Health and Human Services Office of the National Coordinator for Health Information Technology (2007). Dr. Brennan is a 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 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 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 University 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, behavior, 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 2 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. 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 co-chair of the Meaningful Use Workgroup of the Office of the National Coordinator for 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 electronic health records. 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.

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 World Wide Web. 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 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 3 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 midlife, 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 RWJF. 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 Ph.D. 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.

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 the individual level, 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.