# CAPTURING SOCIAL & BEHAVIORAL DOMAINS & MEASURES IN ELECTRONIC HEALTH RECORDS

WILLIAM W. STEAD, M.D.

MCKESSON FOUNDATION PROFESSOR, DEPARTMENTS

OF BIOMEDICAL INFORMATICS & MEDICINE,

CHIEF STRATEGY OFFICER & ASSOCIATE VICE

CHANCELLOR FOR HEALTH AFFAIRS,

VANDERBILT UNIVERSITY

Committee on Recommended Social & Behavioral Domains & Measures for Electronic Health Records (EHRs)

BOARD ON POPULATION HEALTH AND PUBLIC HEALTH PRACTICE

INSTITUTE OF MEDICINE

OF THE NATIONAL ACADEMIES

### **COMMITTEE MEMBERS**

- NANCY E. ADLER, PH.D. (Co-Chair)
  University of California, San Francisco
- WILLIAM W. STEAD, M.D. (Co-Chair)
  Vanderbilt University

KIRSTEN BIBBINS-DOMINGO, PH.D., M.D.
University of California, San Francisco

PATRICIA F. BRENNAN, R.N., PH.D.
University of Wisconsin-Madison

ANA V. DIEZ-ROUX, M.D., PH.D., M.P.H.

Drexel University School of Public Health

CHRISTOPHER B. FORREST, M.D., PH.D.

University of Pennsylvania and Children's Hospital of Philadelphia

**JAMES S. HOUSE, PH.D.** University of Michigan

GEORGE HRIPCSAK, M.D., M.S.

Columbia University

MITCHELL H. KATZ, M.D.
Department of Health,
County of Los Angeles

ERIC B. LARSON, M.D., M.P.H., M.A.C.P.

Group Health Research Institute

KAREN MATTHEWS, PH.D.

University of Pittsburgh School of Medicine

DAVID A. ROSS, SC.D.

Public Health Informatics Institute
The Task Force for Global Health

DAVID R. WILLIAMS, PH.D., M.P.H.

Harvard School of Public Health

Study Fellow

DEIDRA CREWS, M.D., Sc.M., FASN IOM Gilbert S. Omenn Anniversary Fellow Johns Hopkins University School of Medicine

### **COMMITTEE CHARGE**

### THE COMMITTEE WAS ASKED TO:

- Identify domains for consideration by ONC for Stage 3 meaningful use;
- Determine criteria for selection;
- Identify domains and measures for inclusion in all EHRs;
- Consider implications of incorporating recommended measures into all EHRs; and
- Identify Issues in linking other data systems. INSTITUTE OF

## TIMELINE PHASE 2 PHASE 1 01010101111101010101010101010 111010101010101010101010101 INSTITUTE OF MEDICINE OF THE NATIONAL ACADEMIES

## **Conceptual Frameworks**

- Selected 3 frameworks, Ansari et al., Kaplan et al., and MacArthur Research Network on SES Health Model
  - Frameworks looked at downstream and upstream determinants of health
- Models distinguish between characteristics that influence health that reside at 5 levels:
  - Socio-demographic
  - Psychological
  - Behavioral
  - Social relationships and living conditions
  - Physical and social environment

## CRITERIA to identify candidate domains

1 STRENGTH

RELIABLE &

NSITIVITY

2 USEFULNESS 4 FEASIBILITY

**VALID MEASURES** 

CCESSIDII I

6

INSTITUTE OF MEDICINE

OF THE NATIONAL ACADEMIES

### **USEFULNESS**



**INDIVIDUAL** 



POPULATION HEALTH



**RESEARCH** 

7 . . . .

INSTITUTE OF MEDICINE

OF THE NATIONAL ACADEMIES

### **CANDIDATE DOMAINS**

### 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)

### PSYCHOLOGICAL DOMAINS

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

### BEHAVIORAL DOMAINS

Dietary patterns
Physical activity
Tobacco use and exposure
Alcohol use

## INDIVIDUAL-LEVEL SOCIAL RELATIONSHIPS & LIVING CONDITIONS

Social connections and social isolation Exposure to violence

## NEIGHBORHOODS& COMMUNITIES

Compositional characteristics

## CRITERIA applied to measures

1

STRENGTH

3

RELIABLE & VALID MEASURES

5

**SENSITIVITY** 

2

SEFULNESS

4

**FEASIBILITY** 

6

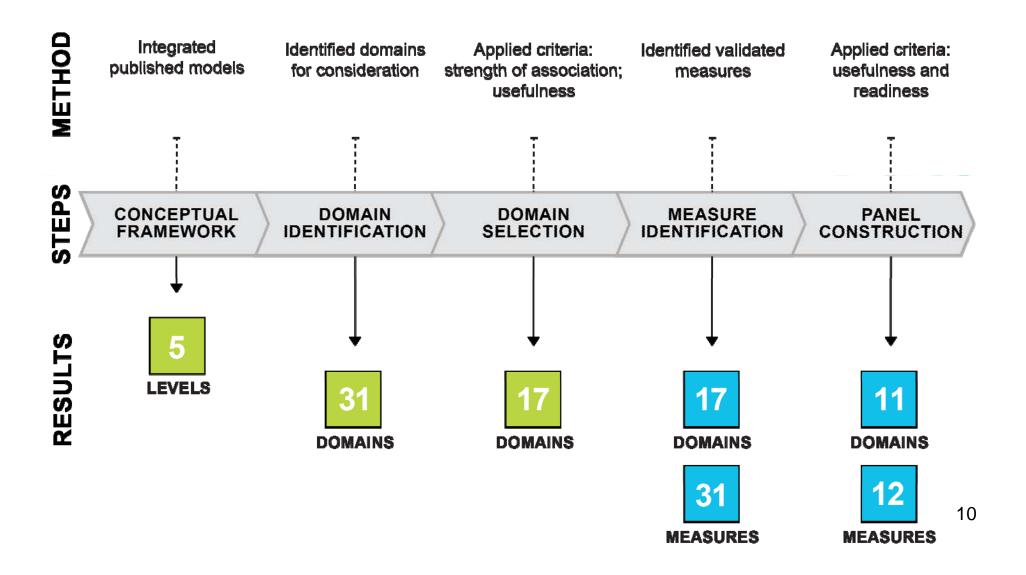
**ACCESSIBILITY** 

9

INSTITUTE OF MEDICINE

OF THE NATIONAL ACADEMIES

### **PROCESS**



### STANDARD DOMAIN MEASURES

	Self-Efficacy: NIH Toolbox
	(10 Q)

- Race/Ethnicity: OMB (2 Q)
- Optimism: LOT-R (6 Q)
- Dietary Pattern: Fruit and Vegetable Consumption (2 Q)
- Race/Ethnicity: U.S. Census (2 Q)
- Education: Educational Attainment (2 Q)
- Physical Activity: Exercise Vital Signs (2 Q)
- Tobacco Use: NHIS (2 Q)
- Social Connection and Isolation: NHANES III (4 Q)
- Neighborhood and Community Compositional Characteristic: Residential address (1 Q)

### Sex Orientation: Self identity (1 Q) Health Literacy: Chew et al (2008) (3 Q)

Q)

Readiness

- Financial Strain: Food Insufficiency (1 Q)
- Anxiety: PROMIS-7a (7 Q)

Employment: MESA (1 Q)

- Anxiety: GAD-7 (7 Q)
- Conscientiousness: Big Five Inventory (1 Q)

- Financial Strain: Overall Financial Resource Strain (1 Q)
- Stress: Elo et al. (2003) (1 Q)
- Depression: PHQ-2 (2 Q)
- Alcohol Use: AUDIT-C (3 Q)
- Neighborhood and Community Compositional Characteristic: Census Tract-Median Income

- Stress: ACE (11 Q)
- Patient Engagement/ Activation: PAM
- Self-Efficacy: Self-efficacy Scales for Specific **Behaviors**
- Sex Orientation: Behavior (1 Q)
- Country of Origin: U.S. Census (2
- Financial Strain: Housing Insecurity (1 Q)
- Physical Activity: Accelometer

**Exposure to Violence: Intimate Partner** Violence: HARK (4 Q)

Depression: PROMIS-8b (8

Usefulness

**NOTE:** Bolded items are domains that are already frequently collected.

**COMMITTEE JUDGMENT** 

1 = 2 =



### **CORE DOMAINS & MEASURES**

### WITH SUGGESTED FREQUENCY OF ASSESSMENT

DOMAIN/MEASURE	MEASURE	FREQUENCY
Alcohol Use	3 questions	Screen and follow up
Race and Ethnicity	2 questions	At entry
Residential Address	1 question (geocoded)	Verify every visit
Tobacco Use	2 questions	Screen and follow up
Census Tract-Median Income	1 question (geocoded)	Update on address change
Depression	2 questions	Screen and follow up
Education	2 questions	At entry
Financial Resource Strain	1 question	Screen and follow up
Intimate Partner Violence	4 questions	Screen and follow up
Physical Activity	2 questions	Screen and follow up
Social Connections & Social Isolation	4 questions	Screen and follow up
Stress	1 question	Screen and follow up

**NOTE:** Domains/Measures are listed in alphabetical order; domains/measures in the shaded area are currently frequently collected in clinical settings; domains/measures not in the shaded area are additional items not routinely collected in clinical settings.

INSTITUTE OF MEDICINE

12

## **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.

## **BENEFITS**

Benefits of including recommended measures in all EHRs include:







MORE EFFECTIVE

TREATMENT

MORE EFFECTIVE POPULATION MANAGEMENT

**DISCOVERY OF LINKAGES** 

## IMPLEMENTATION ISSUES



SELF-REPORTED DATA



PRIVACY PROTECTION



LINKING DATA



RESOURCE CONSIDERATIONS

18

INSTITUTE OF MEDICINE

OF THE NATIONAL ACADEMIES

### **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

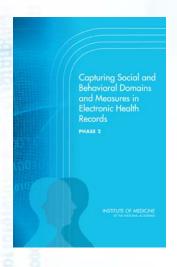
7-3

The Secretary of Health and Human Services should convene a task force within the next three 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 and Medicaid Innovation, the Agency for Healthcare Research and Quality, the Patient-Centered Outcomes Research Institute, the National Institutes for Health, and research experts in social and behavioral science.

## THANK YOU SPONSORS:

The National Institutes of Health
Blue Shield of California Foundation
California HealthCare Foundation
Centers for Disease Control and Prevention
Centers for Medicare & Medicaid Services
The Department of Veterans Affairs
The Lisa and John Pritzker Family Fund
Robert Wood Johnson Foundation
Substance Abuse and Mental Health Services Administration

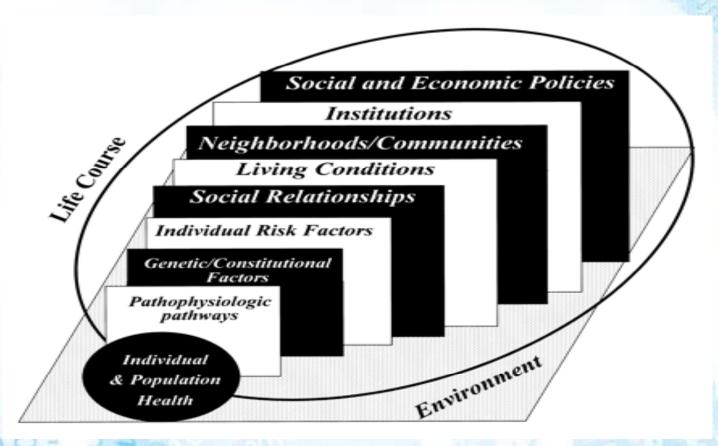
## **QUESTIONS**



THE FULL REPORT IS NOW AVAILABLE FOR FREE DOWNLOAD AT:

iom.edu/ehrdomains2

## Multilevel Model by Kaplan, et al. (2000)



**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).

27
INSTITUTE OF MEDICINE

## **MEASURE VERSUS METRIC**

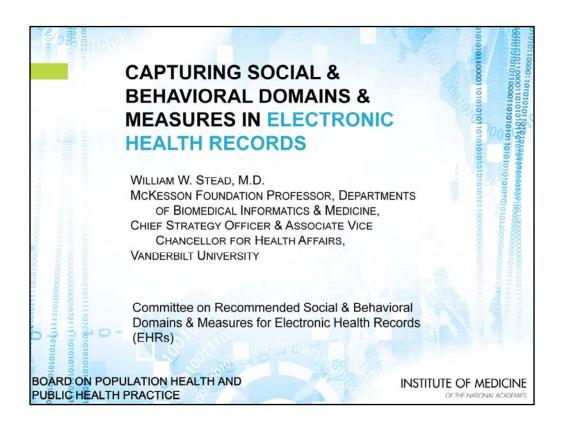
**Example: Physical activity** 

	MEASURE	METRIC	
	Exercise Vital Sign	Metabolic equivalent task minutes (METs)	
	<ol> <li>On average, how many days per week do you engage in moderate to strenuous exercise?         <ul> <li>(0-7)</li> </ul> </li> <li>On average, how many minutes do you engage</li> </ol>	<ul> <li>Light intensity 1.1-2.9</li> <li>Moderate intensity 3.0-5.9</li> <li>Vigorous intensity &gt;=6</li> </ul>	
,	in exercise at this level (blocks of 10 min)		

## STANDARD MEASURE

**Example: Tobacco Use** 

RECOMMENDED SELF REPORTED MEASURE	STAGE 2 MEASURE
NHIS Questions	SNOMED Codes
1. Have you smoked at least 100 cigarettes in your entire life? (Y/N/refused/do not know)	<ul> <li>Current every day smoker</li> <li>Current some day smoker</li> <li>Former smoker</li> <li>Never smoker</li> <li>Smoker, current status</li> </ul>
2. Do you NOW smoke cigarettes every day, some days or not at all?	unknown  •Unknown if ever smoked  •Heavy tobacco smoker  •Light tobacco smoker



### Slide 1:

Good morning. I am Bill Stead and I am briefing you on the report of the Committee on Recommended Social & Behavioral Domains & Measures for Electronic Health Records.



#### Slide 2:

- Outstanding committee, all of whom contributed substantially to the report
- 13 committee members, and 1 fellow
- Spanned public health, informatics, social and behavioral sciences, and clinical practice
- Expertise ranging from pediatrics to gerontology.

### **COMMITTEE CHARGE**

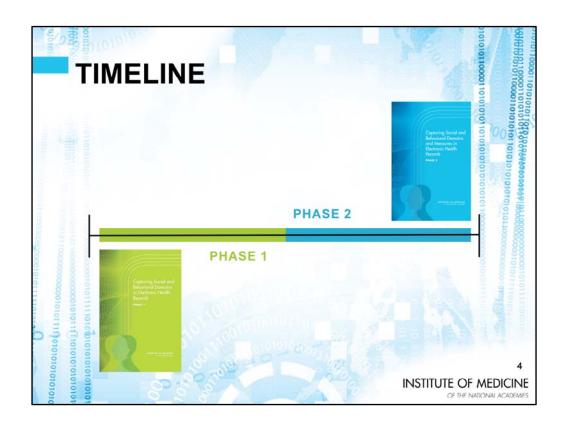
#### THE COMMITTEE WAS ASKED TO:

- Identify domains for consideration by ONC for Stage 3 meaningful use;
- Determine criteria for selection;
- Identify domains and measures for inclusion in all EHRs;
- Consider implications of incorporating recommended measures into all EHRs; and
- Identify Issues in linking other data systems. INSTITUTE OF MEDICINE

#### Slide 3:

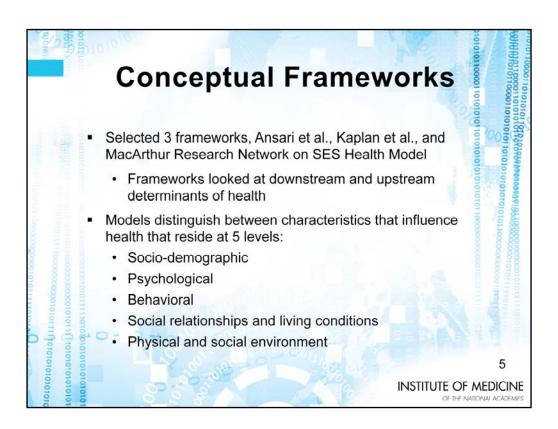
#### THE COMMITTEE WAS ASKED TO:

- Identify domains for consideration by ONC for Stage 3 meaningful use;
- Determine criteria for selection;
- Identify domains and measures for inclusion in all EHRs;
- Consider implications of incorporating recommended measures into all EHRs; and
- Identify Issues in linking other data systems



### Slide 4:

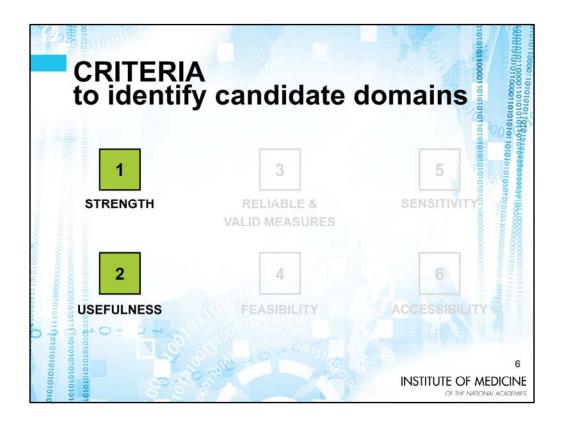
- Because of the timing of deliberations regarding Stage 3 meaningful use of electronic health records (EHRs) we did this in two phases
- The first report was issued on April 8, 2014
- The 2<sup>nd</sup> report was issued on November 13 and incorporates the 1<sup>st</sup> report so that it is comprehensive



### Slide 5:

These conceptual frameworks were used to capture the range of health determinants, and how they are linked to disease onset and progression.

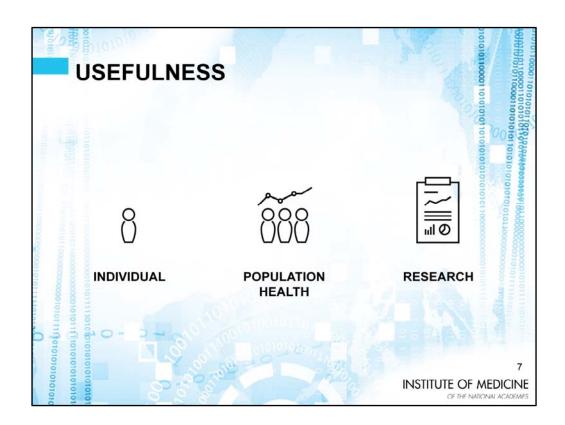
Five levels were identified With 31 domains identified for consideration



### Slide 6:

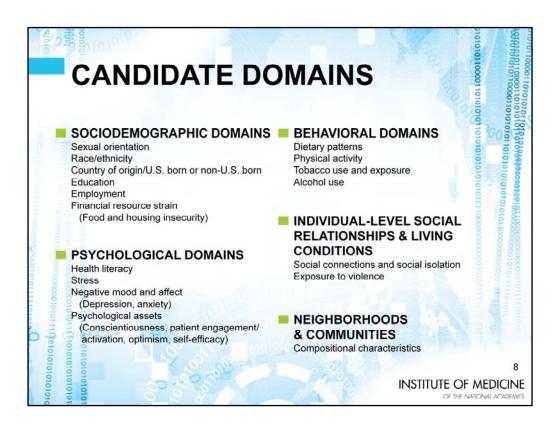
Two criteria were used to identify candidate domains

- One was the strength of the evidence of the association of the domain with health; and
- And the second was usefulness of the domain as measured following three areas [NEXT SLIDE]



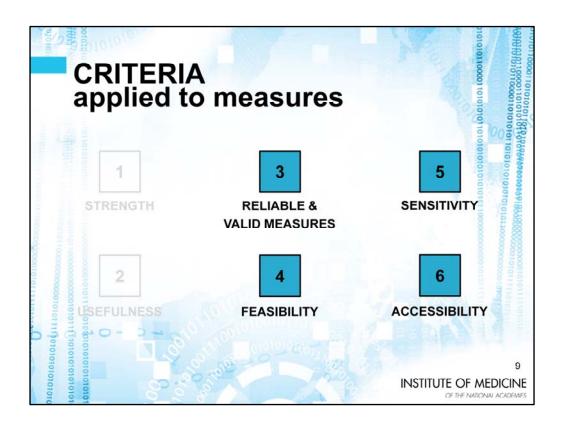
### Slide 7:

- 1. The first area, is improving the health of the individual patient including decision-making between clinician and patient for disease management and treatment,
- 2. The second area, is describing and monitoring population health to inform policy and intervention,
- 3. And, the third area is the value of conducting clinical and population health research in order to accelerate discoveries regarding the causes of health and outcomes of treatment and interventions at multiple levels.



### Slide 8:

Based on these criteria, within the 5 levels, we identified 17 candidate domains as being the best suited for the possible inclusion in all EHRS.

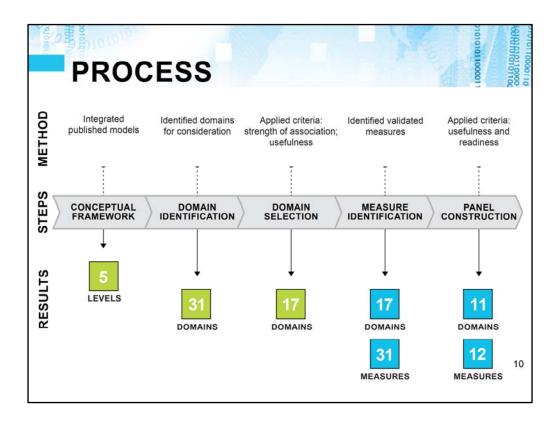


### Slide 9:

The candidate domains, and therefore their measures, had been rated high on association with health and usefulness.

We applied 4 additional criteria to the measures of each domain:

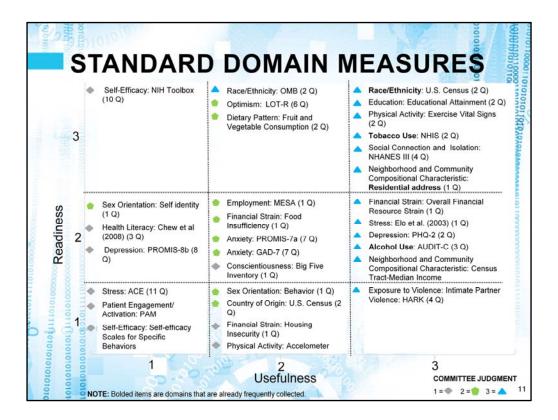
- First: standard representation of a reliable and valid measure that was freely available (no intellectual property issues).
- Second: Feasibility, considering burden placed on the patient, clinical team, or the health system.
- Third, Sensitivity or patient discomfort regarding revealing personal information or increased legal or privacy risks.
- And finally was the accessibility of data from another source, information accessible from another source would be lower priority for inclusion in the EHR.



### Slide 10:

This figure summarizes the methods, steps, and results of the committee's process.

- We identified 31 validated measures for the 17 candidate domains
- Finally, we compared these measures according to the 4 criteria to construct a concise complementary panel with 12 measures of 11 domains



#### **Slide 11:**

This slide shows how the committee compared measures along two dimensions to select a parsimonious panel.

- Readiness (Y axis)—The minimum of the committee's rating on availability of a freely available standard measure, feasibility, and lack of patient discomfort. We used minimum rather than the average because a low rating on any of the 3 increased obstacles to implementation.
- *Usefulness* (X axis)—The committee rating of the usefulness of including the information resulting from the measure in all EHRs focused on its utility in the clinical setting.
- The symbol in front of each measure represents the committee's overall judgment of priority of including the measure in the EHR. [stop here to explain symbols]
- Q is the # of questions in the measure. Chapter 4 of the report lists all of the recommended questions.
- Bolded items are currently routinely collected in EHRs
- After considerable deliberation, the committee decided to include all of the measures in the right column in the recommended panel weighted usefulness over readiness
- It does not mean that the other measures that where not selected are not important. However further development is needed for those measured to be incorporated into EHRS.
- Research need for clinical interventions.

WITH SUGGESTED FREQUENCY OF ASSESSMENT				
DOMAIN/MEASURE	MEASURE	FREQUENCY		
Alcohol Use	3 questions	Screen and follow up		
Race and Ethnicity	2 questions	At entry		
Residential Address	1 question (geocoded)	Verify every visit		
Tobacco Use	2 questions	Screen and follow up		
Census Tract-Median Income	1 question (geocoded)	Update on address change		
Depression	2 questions	Screen and follow up		
Education	2 questions	At entry		
Financial Resource Strain	1 question	Screen and follow up		
Intimate Partner Violence	4 questions	Screen and follow up		
Physical Activity	2 questions	Screen and follow up		
Social Connections & Social Isolation	4 questions	Screen and follow up		
Stress	1 guestion	Screen and follow up		

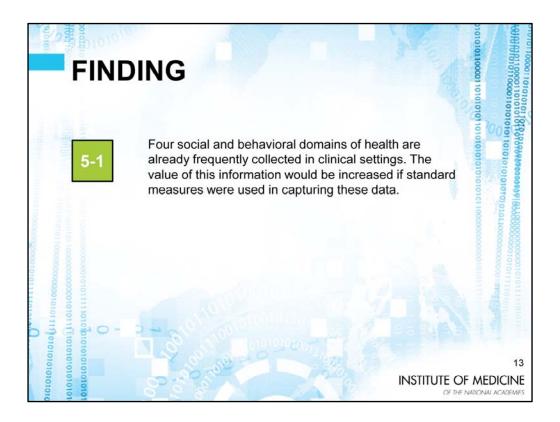
### **Slide 12:**

This table summarizes the domains, the number of questions for each measure and the frequency of screening that the committee suggests.

- The dark shaded domains—alcohol use, race and ethnicity, residential address, and tobacco use—are those that are already routinely collected
- We sought the briefest possible validated measures for all of the domains—most are 2 questions
- Many of them will not need to be assessed repeatedly which addresses some concerns about burden

Taken together these measures provide a concise and coherent overview.

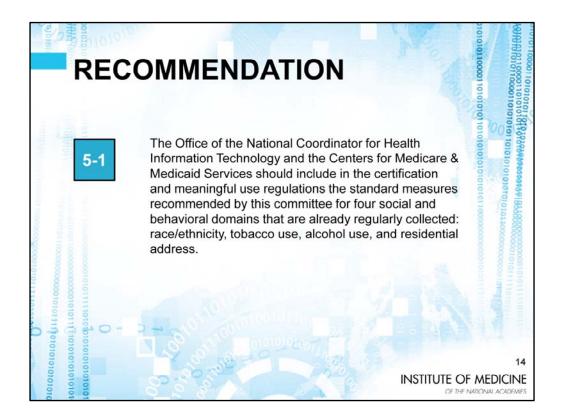
The next few slides present the key findings regarding which measures the Committee recommended.



### **Slide 13:**

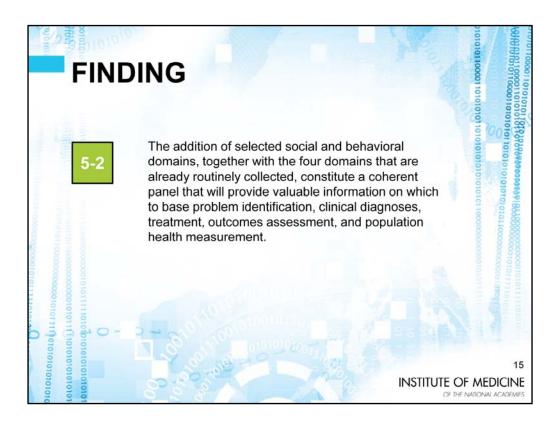
Our first finding—

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 (or specific questions) were used in capturing these data.



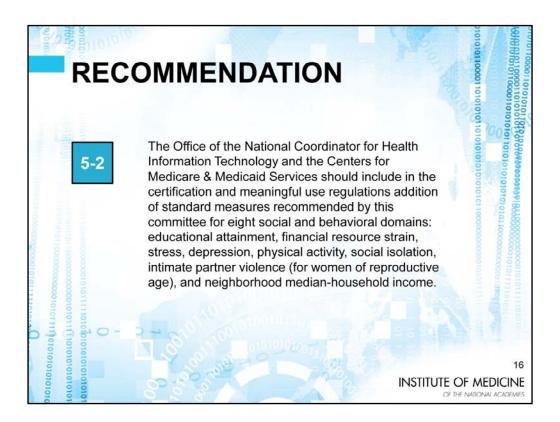
### **Slide 14:**

Therefore the committee recommends that ONC and CMS 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.



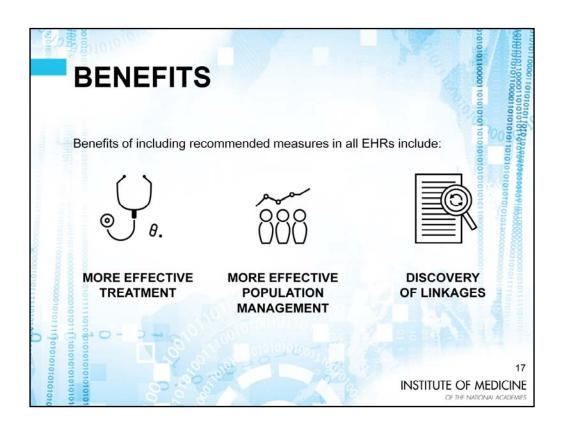
## **Slide 15:**

Our second finding—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.



### **Slide 16:**

Our second recommendation follows this finding—ONC and CMS 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.



### **Slide 17:**

In sum, the Committee believes that including the recommended measures in all EHRs will enable:

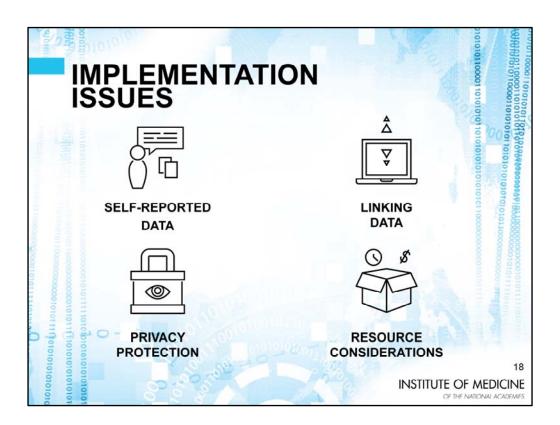
- More effective treatment for individual patients

  For example, identifying depression and inadequate physical activity can improve treatment for patients with diabetes.
- More effective population management for health care systems and for public health agencies,

For example, a health system which finds high rates of socially isolated patients could provide group visits or patient support groups.

• Enhanced opportunities for research that can inform new treatments and interventions to improve individual and population health.

Adding social and behavioral data to clinical and genetic information



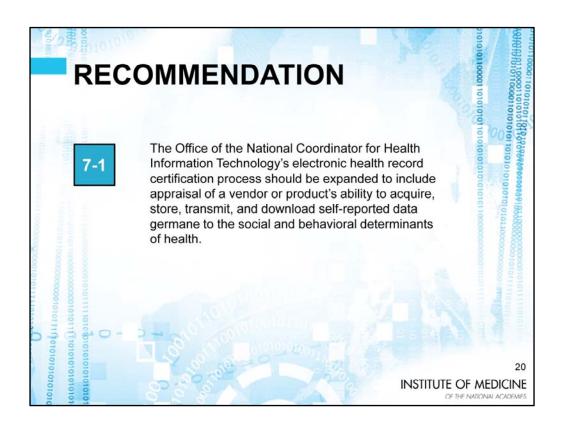
#### Slide 18:

- Implementation issues include modifications to technologies,
- The more challenging issues relate to the expanded view of the determinants of health and adaptation in the way clinical teams work, and how patients participate in their own care and wellness.
- Most of the recommended measures rely on self-reported data, which can be collected directly from the patient on paper or via a computer.
   Practices or health systems need to consider workflow design:
  - When to capture
  - How to review with patient
  - When to intervene
- Data can be shared to reduce data capture burden but transparency about information sharing who & why is critical.
- Links to community agencies and public health can enable concerted intervention for individual patients but may require two way consent [MORE→]
- And while additional time is 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,



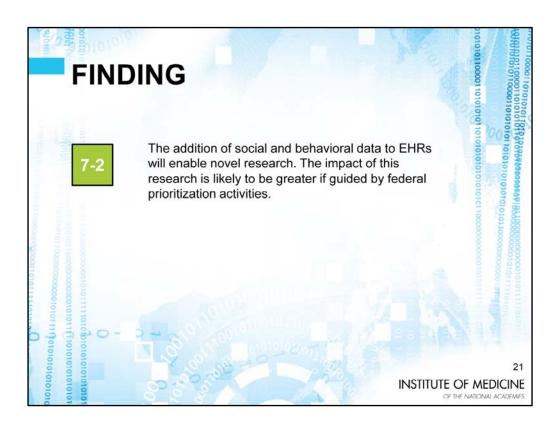
## Slide 19:

This led to our 3rd finding—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.



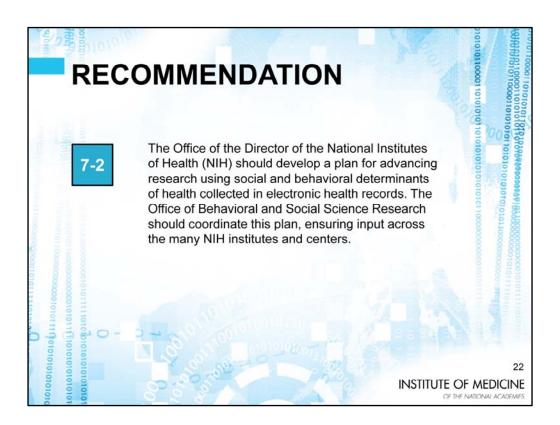
### Slide 20:

Accordingly we recommend that—ONC'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.



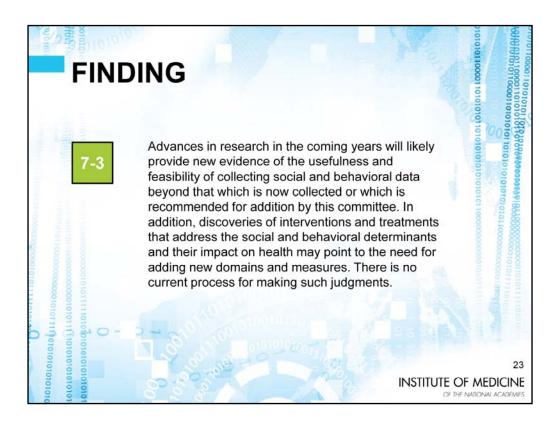
### **Slide 21:**

Our 4th finding—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.



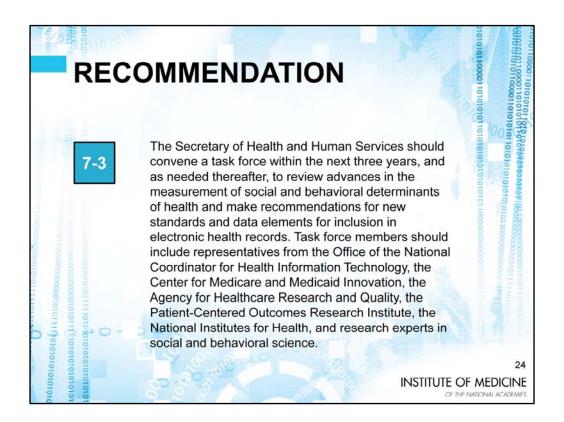
### Slide 22:

And thus the committee recommends—The Office of the Director of 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.



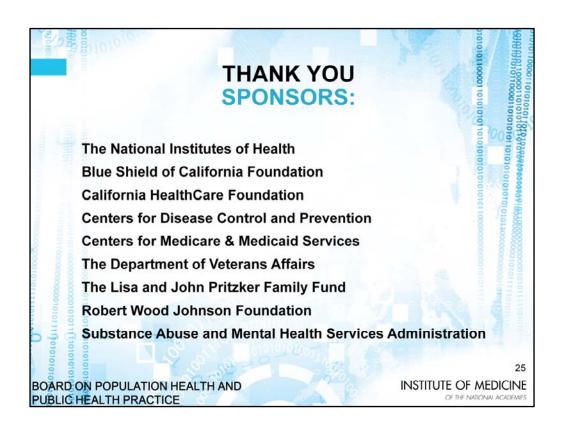
### Slide 24:

Our last finding—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.



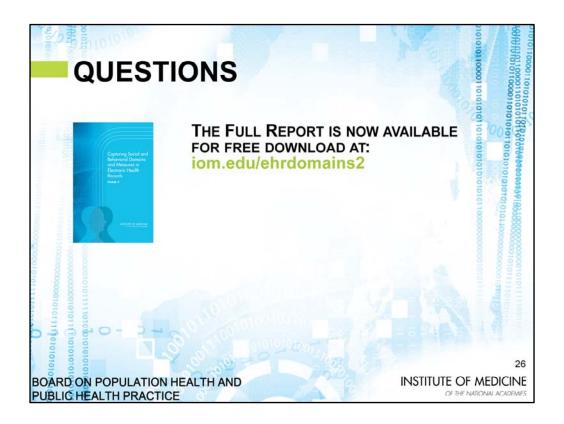
### Slide 25: Bill

Our fifth and final recommendation—The Secretary of HHS 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 ONC, CMS, AHRQ, PCORI, NIH, and research experts in social and behavioral science.



#### Slide 25:

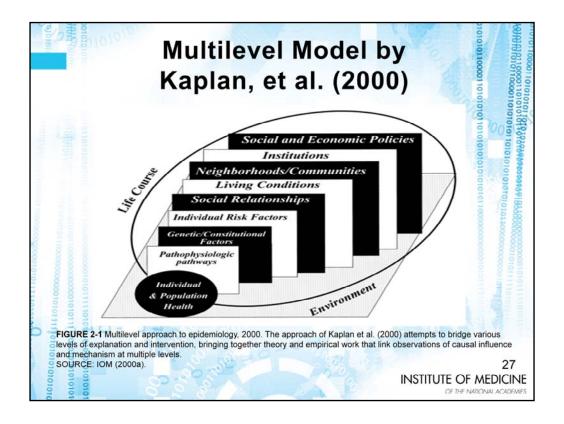
- Thank our study sponsors: the NIH, Blue Shield of California Foundation, California Healthcare Foundation, CDC, CMS, the VA, the Lisa and John Pritzker Family Fund, RWJF, and SAMSHA.
- This was a unique partnership of agencies and foundations that pooled together resources making this study possible.



# Slide 26:

The full report is at iom.edu/ehrdomains2.

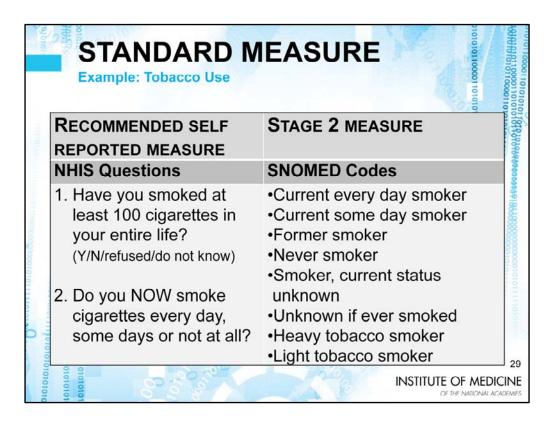
I am now happy to take questions and comments.



- The Kaplan model shows how the conceptual frameworks bridge 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
- The committee determined that Individual Risk Factors, Social Relationships, Living Conditions, and Neighborhoods/Communities were within the committee's statement of task. The other levels were out of the committee's scope of work.

MEASURE	METRIC	
Exercise Vital Sign	Metabolic equivalent task minutes (METs)	
<ol> <li>On average, how many days per week do you engage in moderate to strenuous exercise?         <ul> <li>(0-7)</li> </ul> </li> <li>On average, how many minutes do you engage in exercise at this level (blocks of 10 min)</li> </ol>		

- Moderate intensity brisk walk or gardening
  Vigorous running
- #min moderate or vigorous x 4.5 (mid point of moderate)



Answers: Yes, no, refused, do not know

Mapping:		>=100	Now
Current every day		Υ	every day
Current some day		Υ	some day
Former smoker		Υ	not at all
Never smoker	N	not at all	
Smoker current status unkown		У	refused or do not know
Unk if ever		refused or do not know	