

# Grid-Enabled Measures (GEM) : A Decision Tool to Promote the Use of Standardized Measures and Data Sharing

CRN Research Interactive Forum

February 10, 2011

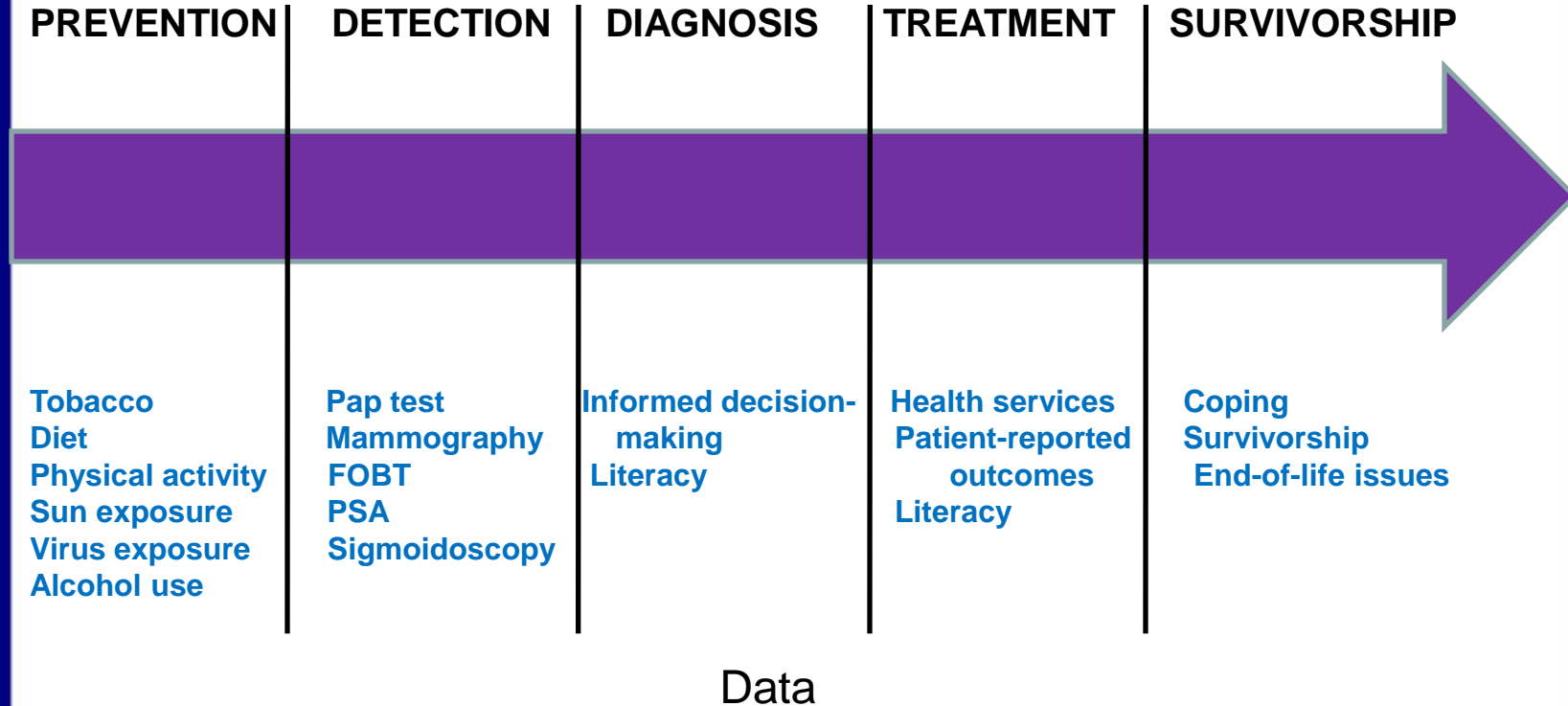
Rick P. Moser, Ph.D.  
Research Psychologist  
Behavioral Research Program



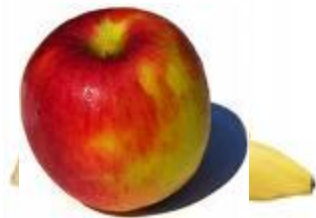
<https://www.gem-beta.org/>

# Unprecedented Access to Cancer-Related Data

## The Cancer Control Continuum



# ...But the Data Aren't Well Integrated



# For the Public's Health: The Role of Measurement in Action and Accountability



INSTITUTE OF MEDICINE  
OF THE NATIONAL ACADEMIES

## Recommendation 2

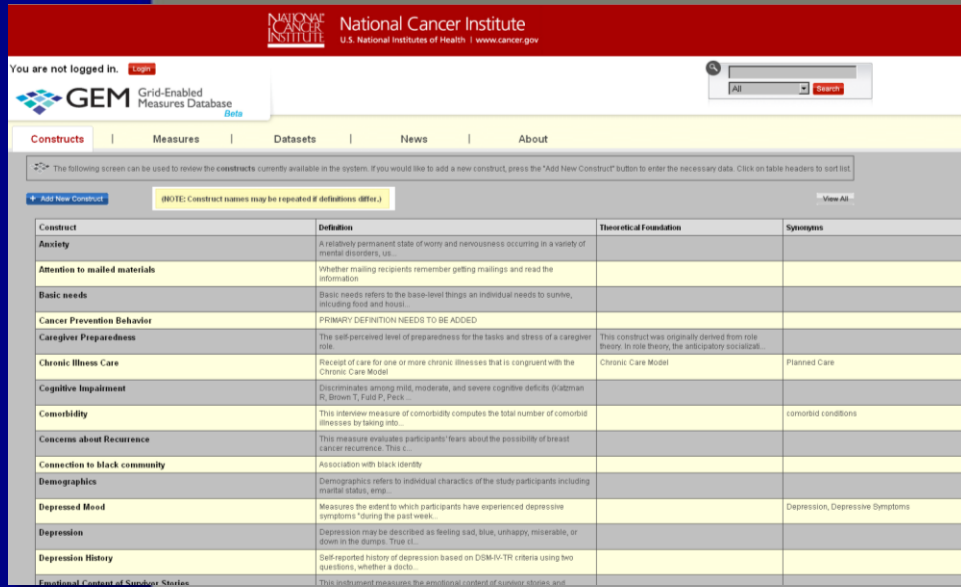
The committee recommends that the Department of Health and Human Services support and implement the following to **integrate, align, and standardize health data and health outcome measurement at all geographic levels:**

The committee finds that at all levels of American life—including local, state, and national—decision makers lack sufficient information to make important choices about the health of their communities. A core, standardized set of indicators that can be used to assess the health of communities.

b. A core, standardized set of health-outcome indicators for national, state, and local use..... **(IOM, December, 2010)**

<http://www.nap.edu/catalog/13005.html>

# Grid Enabled Measures (GEM): Science 2.0



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**NATIONAL CANCER INSTITUTE** National Cancer Institute  
U.S. National Institutes of Health | [www.cancer.gov](http://www.cancer.gov)

**GEM** Grid-Enabled Measures Database [Beta](#)

Constructs | Measures | Datasets | News | About

The following screen can be used to review the constructs currently available in the system. If you would like to add a new construct, press the "Add New Construct" button to enter the necessary data. Click on table headers to sort list.

[+ Add New Construct](#) (NOTE: Construct names may be repeated if definitions differ.) [View All](#)

| Construct                                 | Definition   | Their ethical Foundation   | Synonyms                        |
|---|--|--|---------------------------------|
| <b>Anxiety</b>                            | A readily permanent state of worry and nervousness occurring in a variety of mental disorders, us...         |  |                                 |
| <b>Attention to mailed materials</b>      | Whether mailing recipients remember getting mailings and read the information                                |  |                                 |
| <b>Basic needs</b>                        | Basic needs refers to the basic-level things an individual needs to survive, including food and housing.     |  |                                 |
| <b>Cancer Prevention Behavior</b>         | PRIMARY DEFINITION NEEDS TO BE ADDED   |  |                                 |
| <b>Caregiver Preparedness</b>             | The self-perceived level of preparedness for the tasks and stress of a caregiver role.                       | This construct was originally derived from role theory. In role theory, the anticipatory socializat... |                                 |
| <b>Chronic Illness Care</b>               | Receipt of care for one or more chronic illnesses that is congruent with the Chronic Care Model              | Chronic Care Model   | Planned Care                    |
| <b>Cognitive Impairment</b>               | Discriminates among mild, moderate, and severe cognitive deficits (Jadman R, Brown T, Fuld P, Peck...        |  |                                 |
| <b>Comorbidity</b>                        | This interview measure of comorbidity computes the total number of comorbid illnesses by taking into...      |  | comorbid conditions             |
| <b>Concerns about Recurrence</b>          | This measure evaluates participants' fears about the possibility of breast cancer recurrence. This c...      |  |                                 |
| <b>Connection to Black community</b>      | Association with black identity  |  |                                 |
| <b>Demographics</b>                       | Demographics refers to individual characteristics of the study participants including marital status, ems... |  |                                 |
| <b>Depressed Mood</b>                     | Measures the extent to which participants have experienced depressive symptoms "during the past week."       |  | Depression, Depressive Symptoms |
| <b>Depression</b>                         | Depression may be described as feeling sad, blue, unhappy, miserable, or down in the dumps. True et...       |  |                                 |
| <b>Depression History</b>                 | Self-reported history of depression based on DSM-IV-TR criteria using two questions, whether a dichot...     |  |                                 |
| <b>Emotional Content of Study Studies</b> | This construct measures the emotional content of study studies, not...                                       |  |                                 |

- Architecture for participation
- Data driven decisions
- Wisdom of the masses

## Overall Goals:

To facilitate a virtual community of scientists using collaborative web technology to:

- vet and promote the use of standardized measures—based on theoretically-meaningful constructs;
- share the resulting harmonized data.

<https://www.gem-beta.org/>

# Comparison to Other Measurement Systems



**NIH Toolbox**

Assessment of Neurological and Behavioral Function

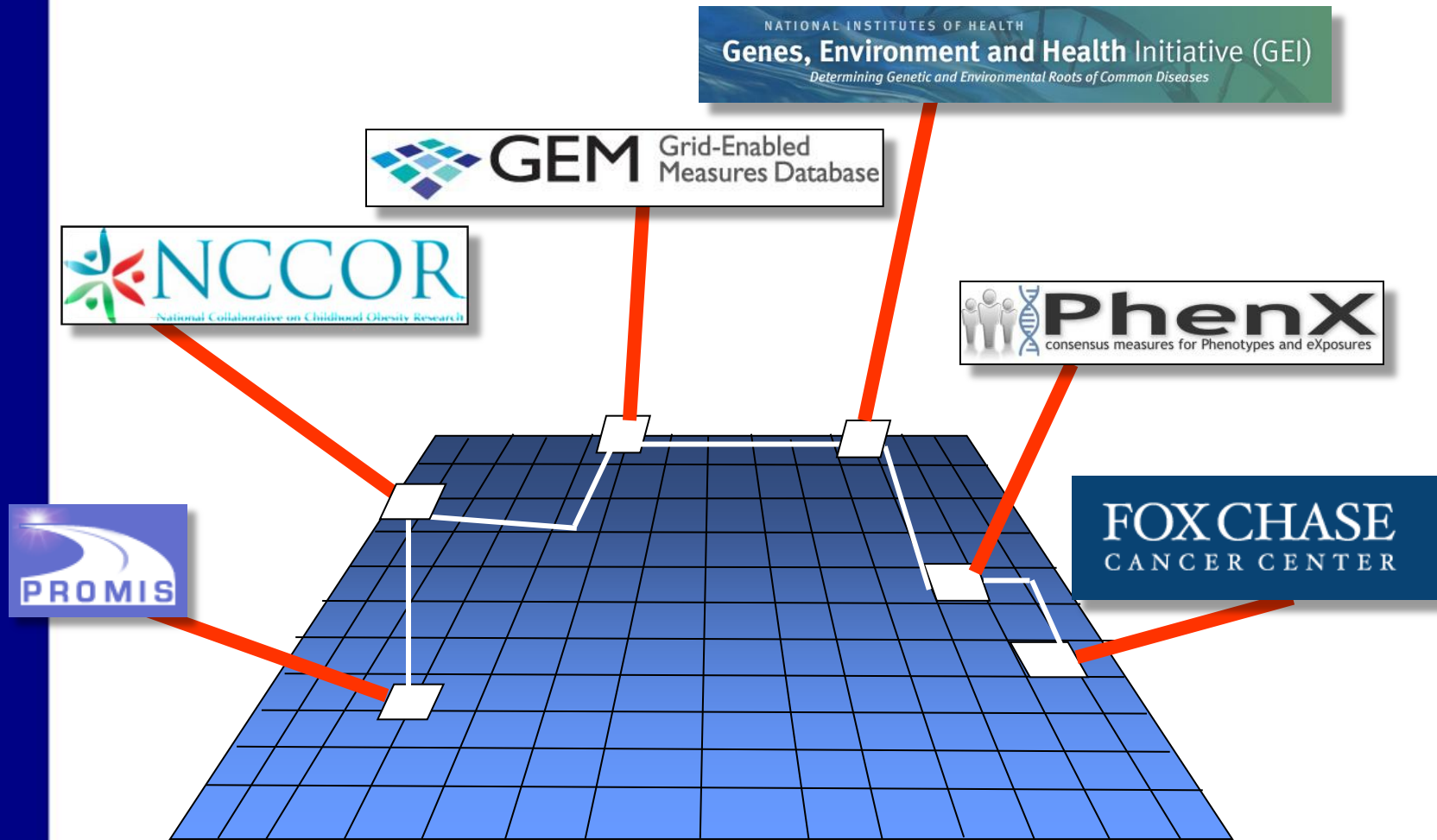
EMOTION



**Patient-Reported Outcomes Measurement Information System**

*Dynamic Tools to Measure Health Outcomes From the Patient Perspective*

# The Power of the Grid: Connecting Data Systems



NATIONAL INSTITUTES OF HEALTH  
**Genes, Environment and Health Initiative (GEI)**  
*Determining Genetic and Environmental Roots of Common Diseases*

 **GEM** Grid-Enabled Measures Database

 **NCCOR**  
National Collaborative on Childhood Obesity Research

 **PhenX**  
consensus measures for Phenotypes and eXposures

**FOX CHASE**  
CANCER CENTER

 **PROMIS**

# Data Sharing: Use Case Scenario

| ID  | VarX | VarY |
|-----|------|------|
| 101 | 2.3  | 1    |
| 102 | 1.2  | 1    |
| 103 | 4.9  |      |



| ID  | VarX | VarY |
|-----|------|------|
| 201 | 3.5  | 0    |
| 202 | 2.7  | 0    |
| 203 | 1.8  | 0    |

The following screen can be used to review the Datasets currently available in the system. If you v

+ Add New Dataset

Page(s) 1

| Dataset Name | Data Collection Start | Data Collection End | Organizational Ho |
|--------------|-----------------------|---------------------|-------------------|
| HINTS 2005   | 2005                  | 2006                |                   |
| HINTS 2008   | 2008                  | 2009                |                   |
| Test Demo    |                       |                     |                   |

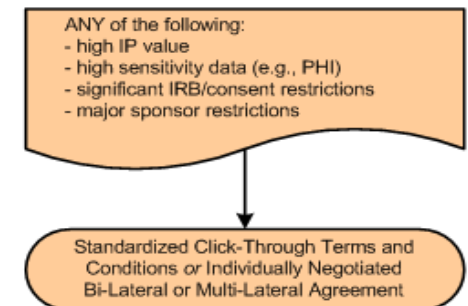
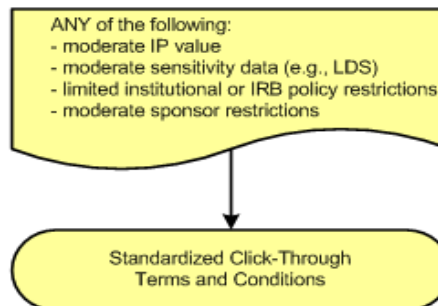
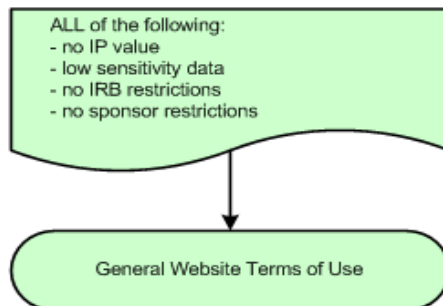
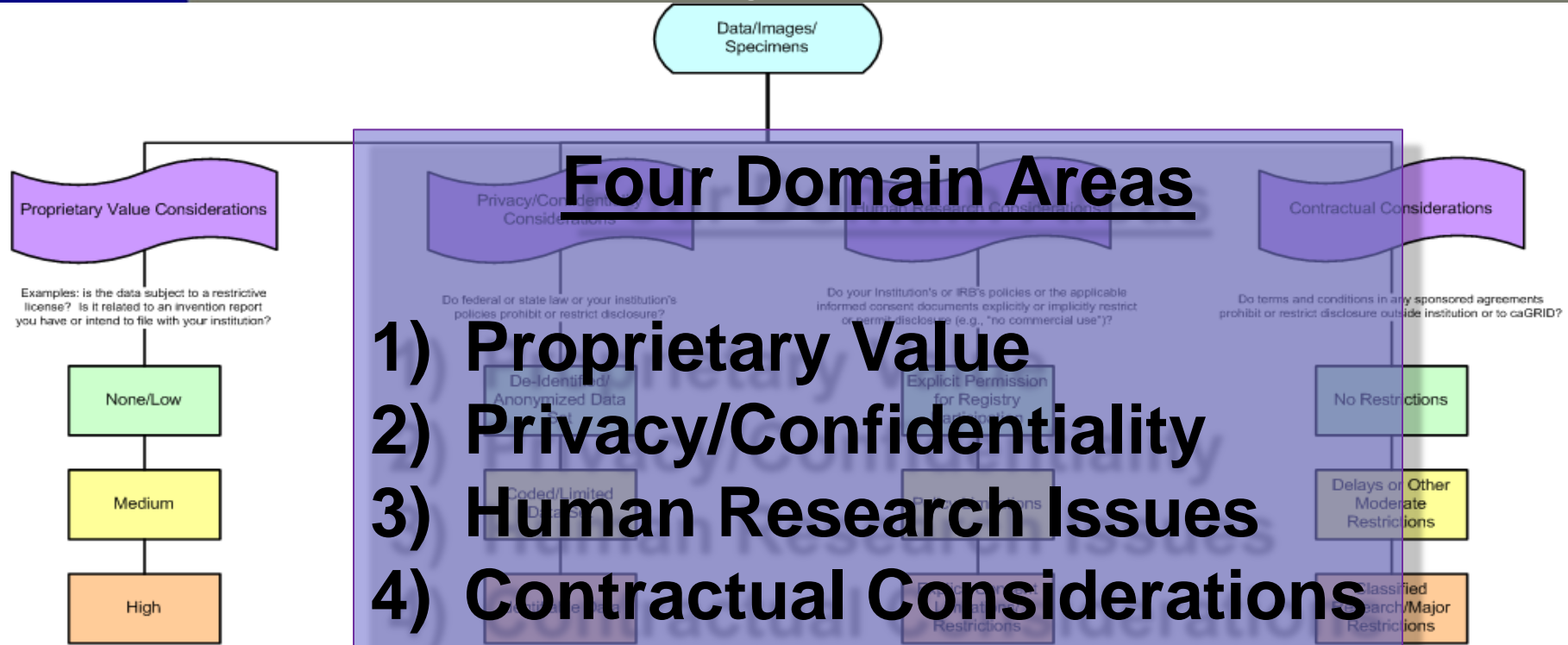
This is just some additional info about the dataset like what study it was associated with or someth...

Questions or feedback?

203      1.8      0



# Data Sharing Decision Tool: caBIG<sup>®</sup> Data Sharing and Security Framework



# How Can You Be Involved?

- Identify, provide meta-data for constructs and measures
  - Templates available
- Comment, rate on existing measures
- Got data?
- Potential connections to virtual data warehouse
- I want your input!
  - Email me: [moserr@mail.nih.gov](mailto:moserr@mail.nih.gov)



# GEM in Action

SOCIETY of  
BEHAVIORAL  
MEDICINE

## Working with Professional Organizations:

- Propose and vet measures for curation
- Consensus on recommended measures for use in electronic health records (EHRs)
  - Consensus meeting May 2-3, 2011 in Bethesda
  - Contact Maureen Boyle (OBSSR)

for more information: [boylemp@mail.nih.gov](mailto:boylemp@mail.nih.gov)



## American Journal of Preventive Medicine (AJPM) Special Issue

- Special supplement on cyberinfrastructure
- Published by Spring, 2011



# Funding Opportunities

- **OBSSR intends to publish a PAR tentatively entitled, “Systems Science and Health in the Behavioral and Social Sciences” (R01/R21)**
- **SBIR Topic 278: *Data harmonization and advanced computation of population health data***
- **Using Systems Science Methodologies to Protect and Improve Population Health (PAR-08-224 ; R21)**
  - *<http://grants.nih.gov/grants/guide/pa-files/PAR-08-224.html>*



# Current State of GEM

Constructs: 81

Measures: 115

Registered Users: 312



# GEM Team

- **NCI**

- Rick Moser
- Brad Hesse
- Abdul Shaikh
- Paul Courtney
- Erik Augustson
- Gordon Willis
- Glen Morgan
- Sarah Kobrin

- **SAIC**

- Mary Cooper

- **Westat**

- Cindy Helba
- Kerry Levin
- Marsha Dunn
- David Garner
- Katy Caperna




# For More Information.....



<http://cancercontrol.cancer.gov/brp/gem.html>


<http://www.gem-beta.org/>

# HINTS-GEM: Research Community Solicitation/Vetting of HINTS Survey Items


National Cancer Institute  
U.S. National Institutes of Health | www.cancer.gov

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## HINTS - GEM

Using the Grid-Enabled Measures (GEM) database to build the Health Information National Trends Survey (HINTS)

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HINTS-GEM Phase I  
HINTS-GEM Constructs

[Add New Construct](#)

| Construct                            | Definition  |
|--------------------------------------|---|
| <b>Anxiety</b>                       | A relatively permanent state of worry and nervousness occurring in a variety of mental disorders, usually accompanied by compulsive behavior or attacks of panic.   |
| <b>Attention to mailed materials</b> | Whether mailing recipients remember getting mailings and read the information   |
| <b>Basic needs</b>                   | Basic needs refers to the base-level things an individual needs to survive, including food and housing. This construct looks at an individual's ability to provide oneself and one's family with these basic needs.   |
| <b>Body Change Stress</b>            | Body change stress refers to subjective psychological stress that accompanies women's negative and distressing thoughts, emotions, and behaviors resultant from breast cancer and breast surgery. Body change stress is manifest with traumatic stress-like symptoms. |
| <b>Cancer Prevention Behavior</b>    | PRIMARY DEFINITION NEEDS TO BE ADDED  |
| <b>Cancer Prevention Knowledge</b>   | Awareness and understanding of cancer risks and means for preventing or reducing risk of cancer.  |
| <b>Cancer related knowledge</b>      | Knowledge and understanding related to cancer including knowledge of recommendations for cancer prevention, cancer screening, cancer treatment and follow up.   |
| <b>Cancer Risk Perceptions</b>       | Beliefs about cancer risk.  |
| <b>Cancer Screening Knowledge</b>    | Awareness and understanding of the available screening tests for cancer.  |
| <b>Caregiver Preparedness</b>        | The self-perceived level of preparedness for the tasks and stress of a caregiver role.  |



## HINTS - GEM

Using the Grid-Enabled Measures (GEM) database to build the Health Information National Trends Survey (HINTS)

# GEM Website



National Cancer Institute  
U.S. National Institutes of Health | www.cancer.gov

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## Constructs

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## Measures

[+ Add New Construct](#)

(NOTE: Construct names may be repeated if definitions differ.)

| Construct                     | Definition  | Theoretical Foundation  | Synonyms     |
|-------------------------------|---|---|--------------|
| Anxiety                       | State of worry and nervousness resulting from mental disorders, us...                                   |   |              |
| Attention to mailed materials | Whether mailing recipients remember getting mailings and read the information                           |   |              |
| Basic needs                   | Basic needs refers to the base-level things an individual needs to survive, including food and housi... |   |              |
| Cancer Prevention Behavior    | PRIMARY DEFINITION NEEDS TO BE ADDED  |   |              |
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## Datasets

# Datasets Tab



National Cancer Institute

U.S. National Institutes of Health | www.cancer.gov

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| Dataset Name | Data Collection Start | Data Collection End | Organizational Home | Description   | Measures   |
|--------------|-----------------------|---------------------|---------------------|---|--|
| HINTS 2005   | 2005                  | 2006                |                     | This is a field that will be used to record additional information for a dataset and may or may not...  | Hamilton Anxiety Rating Scale , HINTS Health Status Question , Nicotine Dependence Syndrome Scale (NDSS) |
| HINTS 2008   | 2008                  | 2009                |                     | This is just some additional info about the dataset like what study it was associated with or someth... |  |
| Test Demo    |                       |                     |                     |   |  |

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# Datasets Tab: Meta-Data, Measures and Constructs, Preview, Download

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## Dataset Details

### General Information

Dataset Name: HINTS 2005  
Data Collection Mode: Web, Proxy, Biological  
Population: Adults and teens  
Collection Period: January 2005 to May 2006  
Number of Observations: 13  
Availability: Year  
Data Dictionary: Yes  
Keywords: ke  
Additional Information: Th  
Organizational Home:

### Other Attributes:

- Contact name
- Number of observations
- Population
- Data collection mode(s)

### Contact Information

Contact First Name: Da  
Contact Last Name: Ga  
Degree:  
Contact Affiliation:  
Address Line 1: 16  
Address Line 2: RA  
City: Rc  
State: MO  
Zip: 20873  
Country: USA  
Telephone:  
E-mail: davidgarson@westat.com

### Measures & Constructs

| Measure Name                              | ConstructName       |
|---|---------------------|
| Nicotine Dependence Syndrome Scale (NDSS) | Nicotine Dependence |
| Hamilton Anxiety Rating Scale             | Anxiety             |

### References & Links

| References        | PubMed ID | Comment    |
|-------------------|-----------|------------|
| Test reference #1 |           | comment #1 |

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Using the Grid-Enabled Measures (GEM) database to build the Health Information National Trends Survey (HINTS)

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HINTS-GEM Phase I  
HINTS-GEM Constructs

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