

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

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National Cancer Institute



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

DISCLAIMER

- **No Interests to Declare**

Overview

- Forest for the Trees
- GEM
- HINTS GEM

Unprecedented Access to 'Big' Data



So What?



www.youtube.com



VimVzgtDc



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



INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES

Recommendation 2

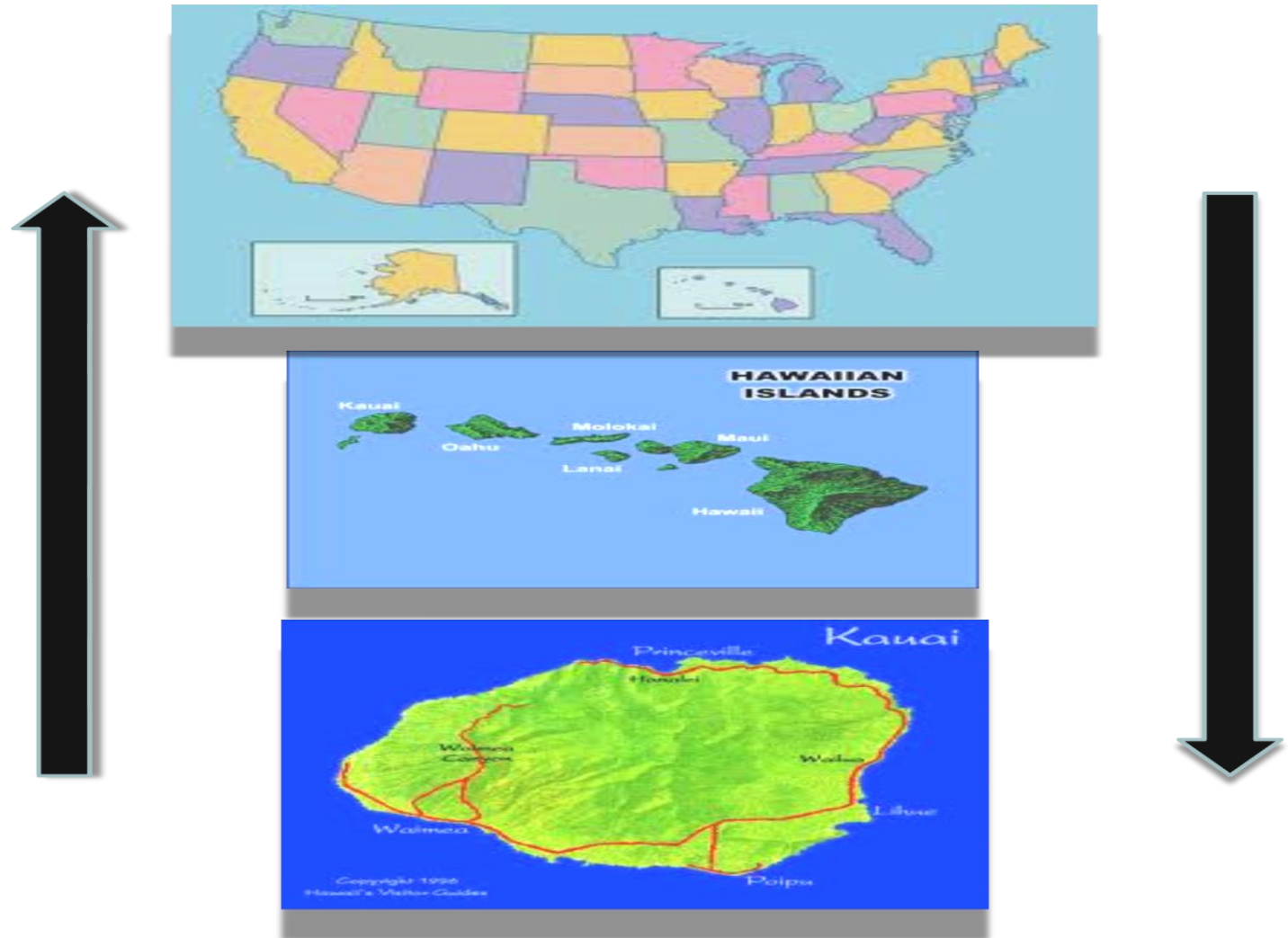
The committee recommends that the Department of Health and Human Services support and implement the following to support the committee's findings that at all levels of American life—including local, state, and national—decision makers lack sufficient information to make important choices about the health of their communities. **integrate, align, and standardize health data and health outcome measurement at all geographic levels:**

a. 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>

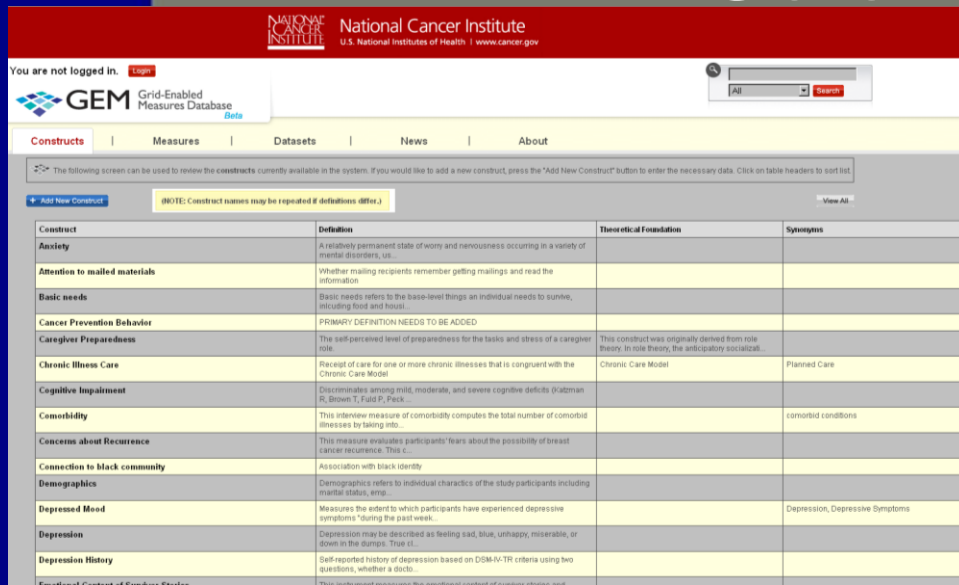
Data Harmonization Across Geographic Levels



...But the Data Aren't Well Integrated



Grid Enabled Measures (GEM): Science 2.0



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

- 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

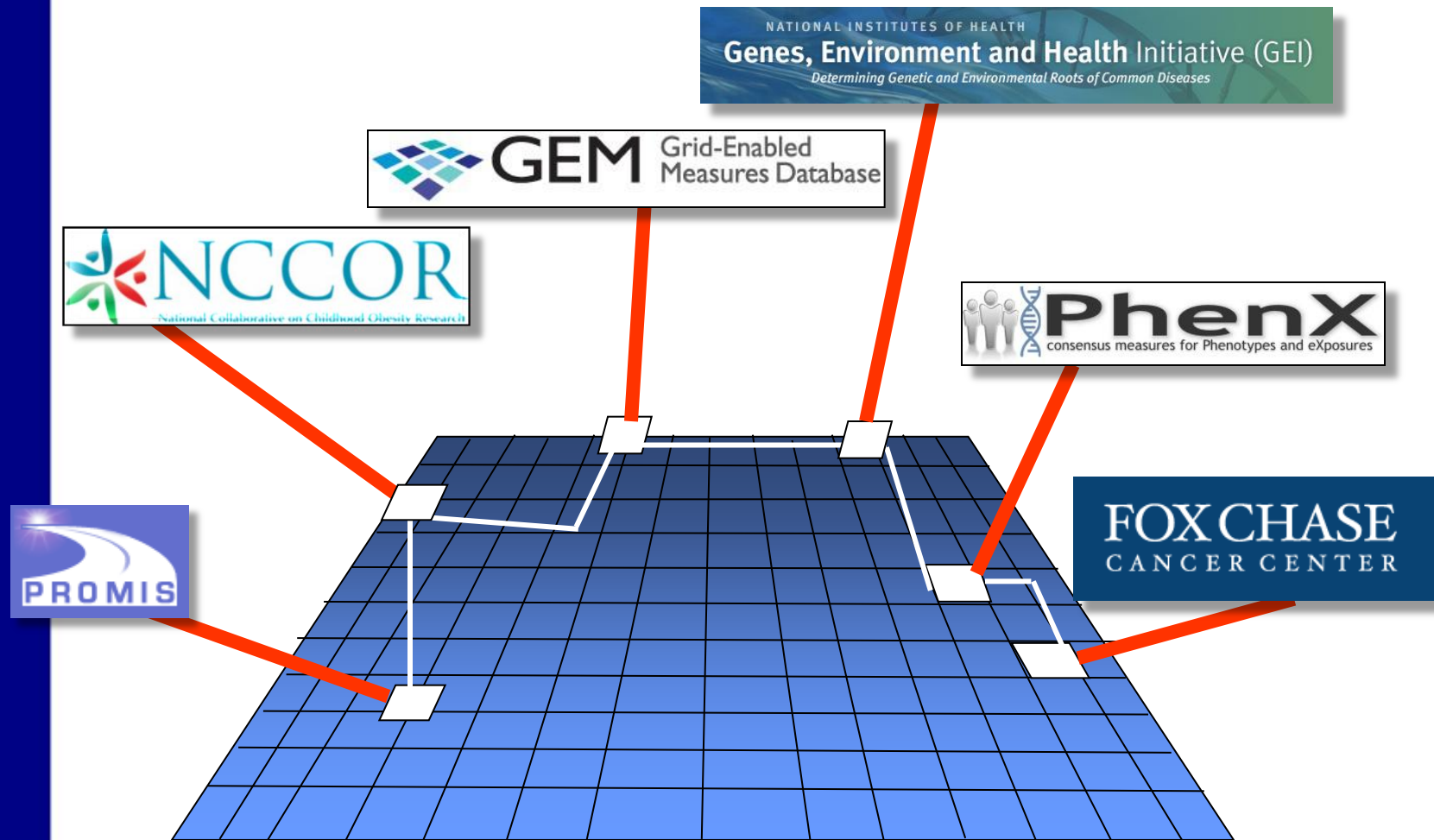
EMOTION



Patient-Reported Outcomes Measurement Information System

Dynamic Tools to Measure Health Outcomes From the Patient Perspective

The Power of the Grid: Connecting Data Systems



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			

Page(s) 1

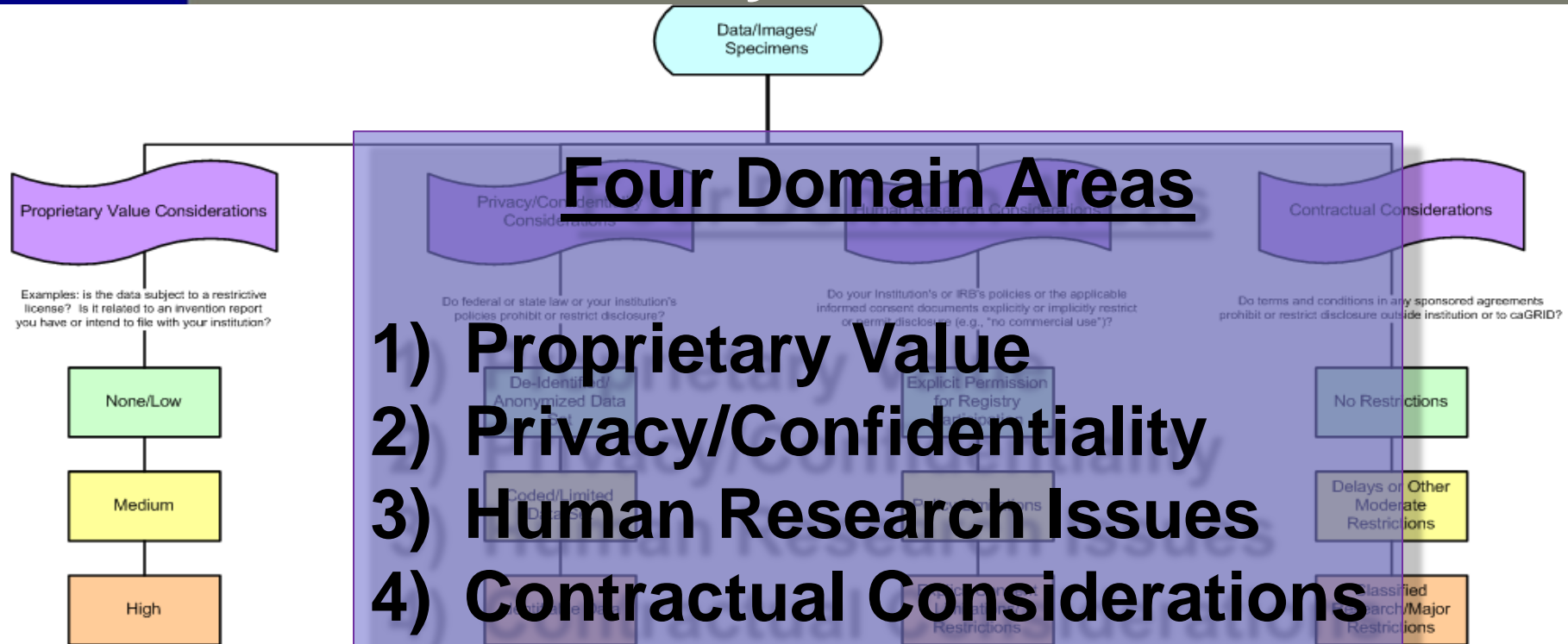
This is just some additional info about the dataset like what study it was associated with or someth...

Questions or feedback?

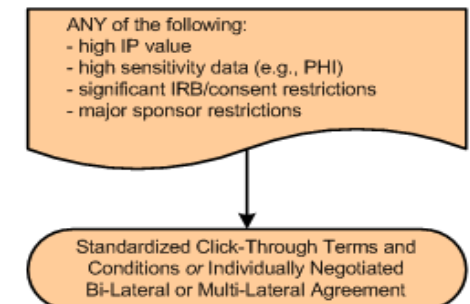
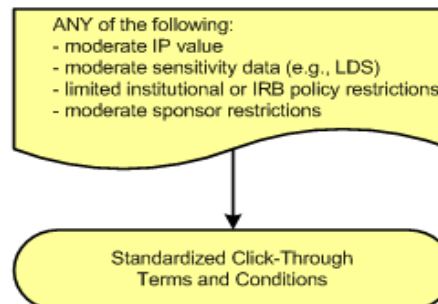
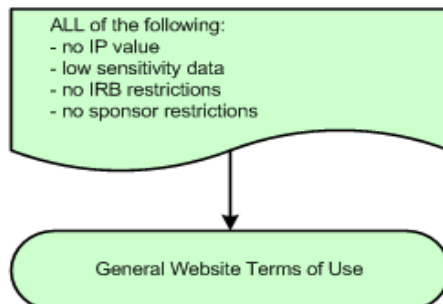
203 1.8 0



Data Sharing Decision Tool: caBIG[®] Data Sharing and Security Framework



- 1) Proprietary Value
- 2) Privacy/Confidentiality
- 3) Human Research Issues
- 4) Contractual Considerations



How Can You Be Involved?

- Identify, provide meta-data for constructs and measures
 - Templates available
- Comment, rate on existing measures
- Got data?
- I want your input!
 - Email Rick Moser:
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)



American Journal of Preventive Medicine (AJPM) Special Issue

- Special supplement on cyberinfrastructure
- Published by Spring, 2011



Current State of GEM

Constructs: 82

Measures: 118

Registered Users: 354



For More Information.....



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

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

A New Application of GEM



<http://hints.cancer.gov/>

<http://secure.mmgct.com/hints-gem/>

HINTS: Health Information National Trends Survey

- Changes in health information environment
- Usage across channels and sources nationally
- Combine channel usage with knowledge, attitudes, behaviors
- Build an evidence base for planners, administrators, communicators, practitioners, and policy makers


HINTS: Methods Overview

- National probability sample of general adult population (18+)
- Surveillance vehicle
- Research vehicle
- Repeated cyclically to track trends
- 2003 and 2005:
 - Computer-Assisted Telephone Interview
 - Random Digit Dial (RDD)
- 2007: Dual frame/dual mode
 - Mail, telephone

HINTS-IV


- Extended Period in the Field
- Four Rounds
- Core Items
- Rotating Modules
- Looking for input on content and specific items


HINTS Website: <http://hints.cancer.gov/>


 HINTS: Health Information National T...

National Cancer Institute


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 **Health Information National Trends Survey**
How Americans find and use cancer information



 **View HINTS Findings**
[HINTS Questions](#)
Survey questions & responses
Respondent characteristics
U.S. adult population estimates
Individual question responses displayed in charts
Question source

[HINTS Resources and Materials](#)
Briefs
Special supplements
Special reports
Factsheets
Brochures


 **Learn About HINTS**
[About HINTS](#)
What HINTS does
How HINTS data are used
HINTS FAQ
NCI presentations
Upcoming events


 **Conduct HINTS Research**
[Public Use Dataset – 02/14/2009](#)
Downloadable SAS, SPSS formats
Registration required
2007, 2005, and 2003 datasets




[Survey Instruments](#)
Sampling plan
Survey instruments
Screening & interview codebooks
Survey administration
Spreadsheet of HINTS items across years

[Research Using HINTS Data](#)
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Suggested journals for publishing HINTS findings

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 **HINTS GEM**
Grid-Enabled Measures Database
Want to have a hand in building the next HINTS survey?
[Get started now >>](#)

Announcements
  **Call for Papers!**
[HINTS RFP released!](#)
[Presentations and posters](#) from the 2009 HINTS Data Users Conference are now available.
[HINTS Briefs: Number 17](#)
Smokers' Attitudes Toward Potential "Reduced-Exposure" Tobacco Products (PREPs)

[Analytic Methods to](#)


HINTS GEM

- HINTS-GEM
 - Developed as a way to build HINTS-IV
- HINTS-GEM will be used to:
 - Propose new Constructs and Measures for HINTS
 - Comment on and rate Constructs and Measures
 - Keep a community of researchers informed about HINTS

HINTS GEM


- **And more:**
 - A link to GEM
 - Another step towards getting behavioral and population science on the Grid
 - An exciting experiment to test best practices for putting federally-funded health research into the hands of the public

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



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

Logout




HINTS - GEM

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

Search

Construct | Measure | News | About



HINTS-GEM Phase I
HINTS-GEM Constructs

Add New Construct

Construct	Definition
<u>Anxiety</u>	A relatively permanent state of worry and nervousness occurring in a variety of mental disorders, usually accompanied by compulsive behavior or attacks of panic.
<u>Attention to mailed materials</u>	Whether mailing recipients remember getting mailings and read the information
<u>Basic needs</u>	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.
<u>Body Change Stress</u>	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.
<u>Cancer Prevention Behavior</u>	PRIMARY DEFINITION NEEDS TO BE ADDED
<u>Cancer Prevention Knowledge</u>	Awareness and understanding of cancer risks and means for preventing or reducing risk of cancer.
<u>Cancer related knowledge</u>	Knowledge and understanding related to cancer including knowledge of recommendations for cancer prevention, cancer screening, cancer treatment and follow up.
<u>Cancer Risk Perceptions</u>	Beliefs about cancer risk.
<u>Cancer Screening Knowledge</u>	Awareness and understanding of the available screening tests for cancer.
<u>Caregiver Preparedness</u>	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

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 the table headers to sort list.

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		
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Cognitive Impairment	Discriminates among mild, moderate, and severe cognitive		

Datasets

Datasets Tab



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GEM Grid-Enabled
Measures Database
Beta

All

Constructs

Measures

Datasets

News

About



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

+ Add New Dataset

View All

Page(s) 1

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					

Page(s) 1

Questions or feedback?

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

Hello rpm39 Logout



Constructs | Measures | **Datasets** | News | About

[Return](#) [Preview](#) [Download](#) [Edit](#) [History](#)

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: Yes
Data Dictionary:
Keywords:
Additional Information:
Organizational Home:

Other Attributes:

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

Contact Information

Contact First Name:
Contact Last Name:
Degree:
Contact Affiliation:
Address Line 1:
Address Line 2:
City:
State:
Zip:
Country:
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

HINTS - GEM



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Logout



HINTS - GEM

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



Search

Construct

Measure

News

About



HINTS-GEM Phase I

HINTS-GEM Constructs

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<u>Caregiver Preparedness</u>	The self-perceived level of preparedness for the tasks and stress of a caregiver role.

HINTS – GEM Proposed Tobacco Items

- Core:
 - Smoking Status
 - Frequency & Amount
 - Use of Menthol
 - Quit HX & Intent

HINTS – GEM Proposed Tobacco Items

- Module:
 - Regulation Knowledge & Perception
 - Use of Alternative Tobacco Products
 - Risk/Harm Perception
 - Use of Quitlines & Web-based Cessation

Participate in HINTS GEM



<http://hints.cancer.gov/>

<http://secure.mmgct.com/hints-gem/>

Viva La Data Revolution!

