

HINTS-GEM: Using Science 2.0 to Facilitate Data Integration in Constructing a National Health Survey

2012 Federal CASIC Workshops

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I want to make sure I acknowledge my co-authors in the first column; MMG is the main contractor for HINTS-GEM

Emergence of the Participative Web

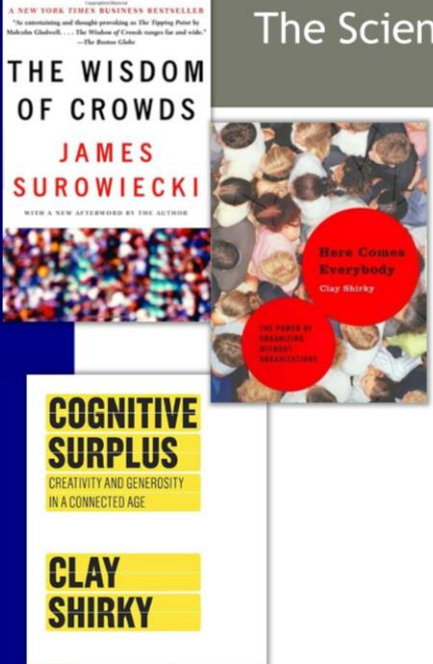


- **Characteristics of Web 2.0**
- Platforms for Participation
- Harnessing “Collective Intelligence”
- Data as the new “Intel Inside”

Time Magazine, 2006

Graphic: Time magazine cover from 2006 that says that “You” were the person of the year.

The Science of Crowdsourcing



The Wisdom of Crowds
JAMES SUROWIECKI
WITH A NEW AFTERWORD BY THE AUTHOR

COGNITIVE SURPLUS
CREATIVITY AND GENEROSITY
IN A CONNECTED AGE
CLAY SHIRKY

Here Comes Everybody
Clay Shirky

THE SCIENCE OF
MANAGING
GROUPS
AND ORGANIZATIONS

Conditions Necessary

- Independence of opinion
- Decentralization
- Mutual goal
- Diversity
- Aggregation
- Incentives (ROI)

Graphic: Covers of three books all related to the use of Crowdsourcing.

Science in a New Collaborative Environment



Graphic: Three pictures that relate to the new interconnected world: 1) A blog; 2) Wikipedia; 3) Amazon.com rating tool.

We live in a new connected world that is supported by collaborative web technology that allows to work together in different ways..

With the rapid increase in the use of the Internet and its capabilities, scientists are taking advantage of collaborative web technology to accelerate discovery in a new participative environment, a phenomenon referred to as Science 2.0. This builds off the idea of Web 2.0—defined by technologies such as wikis, blogs and other means for sharing information and collaborating with other users (e.g., seeing comments and ratings by users of Amazon.com) with specific application to the scientific arena.

Health Information National Trends Survey <http://hints.cancer.gov>



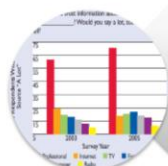
Surveillance and Research Vehicle

- Nationally representative probability sample of general adult population (18+)
- Repeated cyclically to track trends
- Knowledge, attitudes, behavior, investment in cancer communication; new communication environment
- Create more effective health communication strategies



Survey Methodology

- **2003, 2005:** Random Digit Dial, Computer-Assisted Telephone Interview
- **2008:** Dual frame/dual mode: Mail and telephone
- **HINTS 4:** Mail survey; Enter field in fall 2011; Four data collection cycles over 3 years (n=14,000)



Public Data Resource

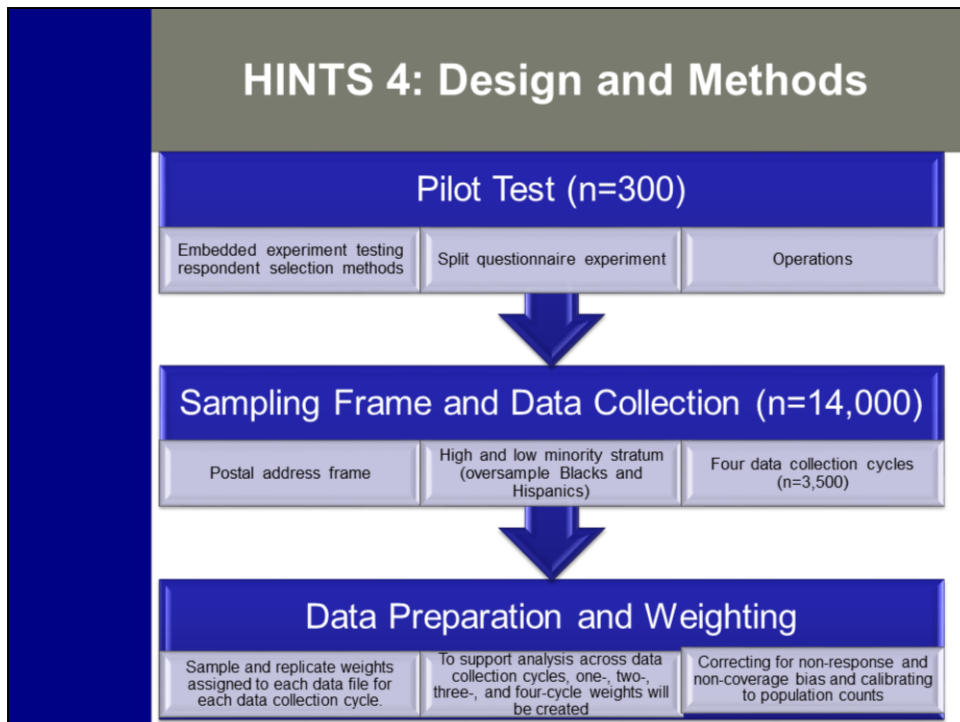
- Electronic codebook
- SAS; STATA; SPSS; Supporting Documents
- Cancer control planning resources
- 100 + peer-reviewed articles

The Health Information national trends survey (HINTS) was created to monitor changes in the rapidly evolving field of health communication. NCI developed this national survey to assess trends in health information usage over time and to periodically conduct fundamental research to assess the basic relationships among cancer-related communication, knowledge, attitudes, and behavior. Data from HINTS can be used to understand how adults use different communication channels to obtain health information, and to create more effective health communication strategies across populations.

HINTS includes items to assess cancer-relevant knowledge, attitudes and behaviors, to explore population responses to investments in cancer communication and to evaluate the impact of changing communication and informatics options on health and cancer-relevant behavior, attitudes and knowledge.

HINTS data are collected periodically to track trends over time in the American public's need for, use of and experiences with cancer information and related behavior and knowledge. The survey was first fielded in 2003 as a RDD survey of over 6000 responded. The RDD methodology was repeated in our 2005 data collection as well. With RDD response rates falling, we implemented HINTS 2007-2008 as a split frame collecting half of our sample through RDD and half through mailed questionnaire. Based on the higher response rates obtained in the mail arm and continuing drop in response rates for RDD, a decision was made to collect the full

sample for HINTS 4 from a mail-based frame. We are currently working on developing the item pool for HINTS 4 and we are aiming to enter the field for data collection again in the fall of 2011.



The next step involves doing a pilot study which will include an embedded test to compare three methods of respondent selection: All adult; Next Birthday, Hagan-Collier. The Hagan-Collier method randomly allocates the selection of specific age-gender populations. In two of seven households, the youngest male is requested. In two of seven, the youngest female is requested. In two of seven, the oldest male is requested; and in one of seven, the oldest female is requested. If there is no eligible person of the proscribed gender, the opposite gender is selected in the same age group.

Sample weights and replicate weights will be calculated for each data collection cycle. Sample weights will permit data users to calculate nationally representative estimates of the population of interest, that is, the adult (18+) non-institutionalized population in the United States--from the collected data. Replicate weights will allow users to compute standard errors for the estimates from the collected data. Because there may be interest by data users in starting their data analyses prior to the completion of all four data collection cycles and because some or all of the non-core questions will not appear in all four data collection cycles, weights will also be created that will allow users to combine across one, two, three or all four cycles.

Grid Enabled Measures (GEM): Science 2.0



- 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 shared measures— based on theoretically-meaningful constructs;
- share the resulting harmonized data.

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

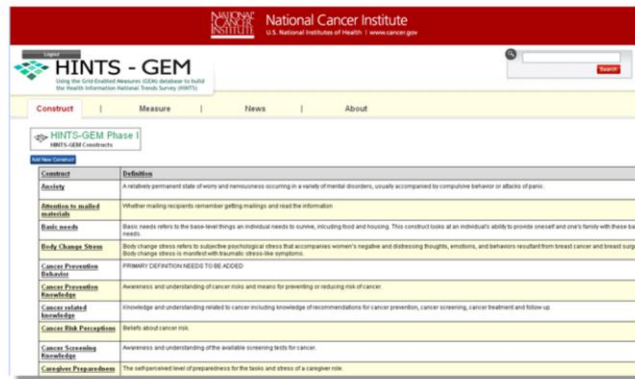


Graphic: Picture of the Grid-Enabled Measures (GEM) website.

What is the GEM in HINTS-GEM?

GEM is an interoperable, dynamic website that facilitates a virtual community of scientists—using collaborative technology—with two goals: 1) promote the use of shared measures—very importantly based on theoretically-meaningful constructs; and 2) Share the resulting harmonized data. GEM uses aspects of Web 2.0 to facilitate the use of shared measures: 1) Architecture for participation: Templates will be made available for researchers to upload their existing measures and associated meta-data; 2) Data driven: Decisions for which measures (and associated constructs) are best for research can be determined by outcomes such as average rating and number of times a measure was used along with traditional metrics found in the metadata (e.g., reliability and validity); 3) Wisdom of the crowd: We believe that a virtual community of researchers can provide their expertise that others can use to make decisions.

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



The screenshot shows the HINTS-GEM website interface. At the top, it features the National Cancer Institute logo and the text "National Cancer Institute U.S. National Institutes of Health | www.cancer.gov". Below this is the "HINTS - GEM" logo and the tagline "Using the Grid-Enabled Measures (GEM) database to build the Health Information National Trends Survey (HINTS)". A navigation bar includes "Construct", "Measure", "News", and "About". The main content area is titled "HINTS-GEM Phase 1 HINTS-GEM Constructs" and displays a table of constructs.

Construct	Definition
Facility	A relatively permanent state of worry and nervousness occurring in a variety of medical disorders, usually accompanied by compulsive behavior or attacks of panic.
Attention to mailed materials	Whether mailing recipients remember getting mailings and read the information.
Basic needs	Basic needs refers to the basic-need 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.
Body Change Stress	Body change stress refers to subjective psychological stress that accompanies women's negative and distressing thoughts, emotions, and behaviors resulting from breast cancer and breast surgery. Body change stress is marked with traumatic stress-like symptoms.
Cancer Prevention Behavior	PRIMARY DEFINITION NEEDS TO BE ACCOED
Cancer Prevention Knowledge	Awareness and understanding of cancer risks and means for preventing or reducing risk of cancer.
Cancer related knowledge	Knowledge and understanding related to cancer including knowledge of recommendations for cancer prevention, cancer screening, cancer treatment and follow-up.
Cancer Risk Perception	Beliefs about cancer risk.
Cancer Screening Knowledge	Awareness and understanding of the available screening tests for cancer.
Catastroph Preparedness	The self-perceived level of preparedness for the risks and stress of a cancer risk.

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

<https://secure.mmhct.com/hints-gem/>

Graphic: Picture of the HINTS-GEM website.

HINTS-GEM is a sub-component of GEM developed for the HINTS community as a way to build HINTS 4 and keep a community of researchers engaged with HINTS over time.

HINTS-GEM was used to:

-Propose new Constructs and Measures for

the next HINTS survey

- Comment on and rate Constructs and Measures

- Keep a community of researchers informed about HINTS

Constructs Tab

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

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

Construct | Measure | News | About

HINTS-GEM Phase I
HINTS-GEM Constructs


Add New Construct


Construct	Definition
Anxiety	A relatively permanent state of worry and nervousness occurring in a variety of mental disorders, usually accompanied by compulsive behavior or attacks of panic.
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 housing. This construct looks at an individual's ability to provide oneself and one's family with these basic needs.
Body Change Stress	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.
Cancer Prevention Behavior	PRIMARY DEFINITION NEEDS TO BE ADDED
Cancer Prevention Knowledge	Awareness and understanding of cancer risks and means for preventing or reducing risk of cancer.
Cancer related knowledge	Knowledge and understanding related to cancer including knowledge of recommendations for cancer prevention, cancer screening, cancer treatment and follow up.
Cancer Risk Perceptions	Beliefs about cancer risk.
Cancer Screening Knowledge	Awareness and understanding of the available screening tests for cancer.
Caregiver Preparedness	The self-perceived level of preparedness for the tasks and stress of a caregiver role.

Graphic: Picture of Constructs tab on HINTS-GEM website.

Construct tab-
Constructs and their definitions

Measures Tab


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



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

Construct | Measure | News | About

HINTS-GEM Phase I
HINTS-GEM Measures

[Add New Measure](#)

Construct	Measure	HINTS Datasets	Status	Source
Cancer Prevention Knowledge	Getting checked regularly for colon cancer increases the chances of finding cancer when it's easy to treat.	2003, 2005	Under consideration	New to HINTS 2003, Revised from: HINTS 2003, question CC-26c
Cancer related knowledge	People with skin cancer would have pain or other symptoms prior to being diagnosed.	2005	Under consideration	New to HINTS 2005
Information scanning from non-clinical sources	About how often have you read such health sections in the past 12 months? Would you say once or more per week, or less than once per week?	2005	Under consideration	New to HINTS 2005
Information scanning from non-clinical sources	About how often have you read this sort of information in the past 12 months?	2005	Under consideration	New to HINTS 2005
Health information seeking	Based on the results of your most recent search for information about health or medical topics, how much do you agree or disagree with the following statements? It took a lot of effort to get the information you needed.	2007	Under consideration	Original to HINTS 2003. Provided by N. Arora.
	Based on the results of your most recent search for information about health or medical topics, how much do you agree or disagree with the following statements? The information you found was hard to understand.	2007	Under consideration	Original to HINTS 2003. Provided by N. Arora.
	Based on the results of your most recent search for information about health or medical topics, how much do you agree or disagree with the following statements? You felt frustrated, unsure, or in search for the	2007	Under consideration	Original to HINTS 2003. Provided by N. Arora.

Graphic: HINTS-GEM Measures Tab

Used to view all measures within a construct, the HINTS data set that the item appeared in, the status of the item for HINTS 4 (under construction, recommended for exclusion, or recommended for inclusion), and the source of the item, which is important for us, given the goal of standardizing measures across surveys. This enables us to see if the items are new, or if they correspond to similar items in BRFSS, Pew, NHIS, etc.

Add a New Measure: Nudging Toward Harmonization

Add New Measure

*Construct: (If the construct you would like to use is not in this list, please [create a new construct](#).)

*Response option type:

*Response options: (separate options with a semicolon)

*Measure:

Specific reasons for including this item in HINTS 4

- This is a trend measure.
- This measure appears on another survey. Specify survey:
- This measure is central to a theory of health behavior. Specify theory:
- This measure is designated in the Cancer Data Standards Registry and Repository. ([caDSR](#)).

Graphic: Adding a new measure using the HINTS-GEM functionality. This slide also shows how users are prompted to provide a reason for including this measure in the HINTS survey and it specifically asks if this measure was used in a previous survey to nudge the reuse of items.

Using a Phased Approach

- **Phase I: HINTS Champions**
 - Recommend existing Measures for inclusion in or exclusion from HINTS 4 or 'under consideration'
 - Propose new Measures and/or Constructs
 - Disseminate HINTS-GEM to respective research community
- **Phase II: HINTS Community**
 - Comment on existing Measures and/or Constructs
 - Propose new Measures and/or Constructs
 - Propose alternative Measures
 - Rate Measures and/or Constructs

Work on HINTS-GEM started in November, 2010 and ended in April, 2011.

Work was done in 2 phases:

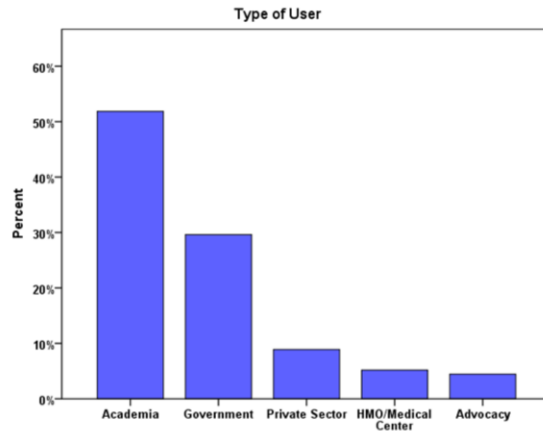
- 1) Enlisting participation from HINTS Champions: Twenty-one HINTS Champions (i.e., individuals who had contributed to HINTS development in the past or who were known by NCI to be HINTS data users) from the extramural research community and internal to NCI were initially invited to be the first HINTS-GEM users in August, 2010. These Champions participated in an on-line HINTS-GEM orientation in September 2010. Champions were assigned content areas (i.e., Constructs) based on their areas of substantive expertise and/or content that they had helped to develop in previous HINTS instruments. Champions were charged with three tasks to complete by the end of October 2010. First, they were asked to review the Measures already contained within HINTS-GEM (i.e., Measures that had appeared in a previous iteration of the survey) and assign the appropriate status to each Measure. If a Champion wanted the Measure to be considered for HINTS 4, then they indicated a status of "Recommended for Inclusion in HINTS 4." If they thought the Measure should be excluded from HINTS 4, they changed the status to "Recommended for exclusion from HINTS 4." Finally, if they wanted a larger community to have input into the decision, they left the Measure's status as "Under Consideration." Second, Champions were asked to populate HINTS-GEM with new Measures for consideration in HINTS 4. Finally, Champions helped to disseminate information about HINTS-GEM to a broader community of research using prepared email blasts and PowerPoint slides for use at conferences or in communication with their respective professional societies.
- 2) Enlisting participation from general users: Concurrently, NCI prepared a larger HINTS-GEM promotion campaign for launch at the 2010 American Public Health Association (APHA) Annual Meeting which was held in early November, 2010 in Denver, Colorado. HINTS Program staff was available on-site during the meeting to demonstrate HINTS-GEM and to register new users to the site. HINTS-GEM Fact Sheets were available at the meeting; information about HINTS-GEM was disseminated via the HINTS website (<http://hints.cancer.gov>); and an email describing HINTS-GEM (and directing potential users to an on-line HINTS-GEM orientation) was sent to all email addresses on record at the HINTS Program. These email addresses represent individuals who had requested to download HINTS data in the past or who had reached out to the HINTS Program for another reason. General HINTS-GEM users had all the same functional capabilities as HINTS Champions except that general users were unable to change the status of Measures.

Periodic email announcements and HINTS-GEM News items were sent and posted to encourage continued participation in HINTS-GEM after the official launch to a broad community of researchers at APHA. The HINTS Program provided technical support to HINTS-GEM users as needed. Communication with the HINTS-GEM community first emphasized adding Measures to HINTS-GEM (November 2010-December 2010), then moved to Commenting on Measures (January 2011), and finally focused on rating Measures in HINTS-GEM (February 2011-March 2011). In March, 2011, all Measures in HINTS-GEM with a status of "Recommended for Inclusion in HINTS 4"

or “Under Consideration” were submitted—as required by all public surveys—to the Office of Management and Budget (OMB) as an “over-inclusive item pool.” This pool represents the group of items that researchers will select from as they work with the HINTS Program to build the HINTS 4 instruments.

Results: Users

- 51 HINTS-GEM Champions
- 87 Additional users



14

Graphic: Bar chart showing the percentage of different stakeholders who participated in HINTS-GEM.

In total, there were 51 HINTS-GEM Champions and an additional 87 users who contributed to HINTS-GEM. Most users came from academia (52%) or government (30%) though the private sector (9%), advocacy groups (4%) and HMO/Medical Centers (5%) were also represented. Although users were required to register in order to participate (for tracking and accountability purposes), they were only asked for their name and affiliation so detailed information about the users is limited.

Results: Measures

- 1173 measures entered across 85 constructs
 - 526 measures from previous iterations
 - 647 new measures proposed
 - 60 alternative measures
- Final item pool submitted to OMB

Measure Disposition	Measures from Previous	Measures Newly Proposed
	HINTS Iterations (n=526)	for HINTS 4 (n=647)
Recommended for inclusion	37.6%	41.7%
Recommended for exclusion	36.5%	6.3%
Under consideration	25.9%	51.9%

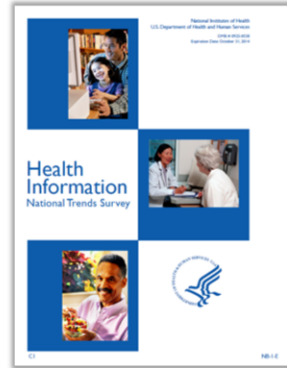
HINTS-GEM was initially seeded with 81 Constructs from GEM and 526 measures from all three previous iterations of HINTS. By the end of the campaign, a total of four new constructs and 647 new measures had been proposed, resulting in a total of 85 Constructs and 1173 Measures in the HINTS-GEM database. The total number of measures (both existing and new) were spread across the constructs with several having a large number of measures (Tobacco Use= 130; Colorectal Cancer= 75, Use of Technology= 69, Health Information Seeking=60) and others having very few measures (for example, Belief in a Just World=1; Religiosity and Spirituality=1). A total of 60 alternative measures were proposed as potential replacements or alterations for existing measures.

Across all measures, the number of comments ranged from 0-8 with 167 (14%) having no comments and a majority (71%) having 1 or 2 comments. Regarding ratings, a large majority had 0 ratings (89%) and for those that were rated, most had only 1 related comment (9%). The ratings themselves tended to be negatively skewed such that 87% of measures with ratings had an average value of 4 or greater (range 1-5, with 5 being the 'best' measure). In regards to the reasons for including a new measure, out of the 647 new measures proposed, the following results were seen: 1) This is a trends measure (4%); 2) This measure appears on another survey (19%); 3) This measure is central to a theory of health behavior (9%); and 4) This measure is designated in the Cancer Data Standards Registry and Repository (0%).

In March, 2011, all Measures in HINTS-GEM with a status of “Recommended for Inclusion in HINTS 4” or “Under Consideration” were submitted—as required by all public surveys—to the Office of Management and Budget (OMB) as an “over-inclusive item pool.”

HINTS 4 Cycle 1 Instrument

- Data available to public summer, 2012
- Approximately half new items
- Core items to be asked on all four iterations
- Emerging areas:
 - Discussions with providers re: screening
 - Electronic medical records



16

Graphic: Cover of HINTS 4 Cycle 1 instrument.

Benefits of Data Harmonization

"Without question, psychology as a field must in some way or another be motivated by a sincere idealistic quest to systematically build a **cumulative base of knowledge** upon which the science of psychology can progress."

Patrick J. Curran, Ph.D
Professor, Department of Psychology
University of North Carolina at Chapel Hill



Graphic: Picture of the cover of a special issue of Psychological Methods dedicated to integrative data analysis.

Facilitates Integrative Data Analysis

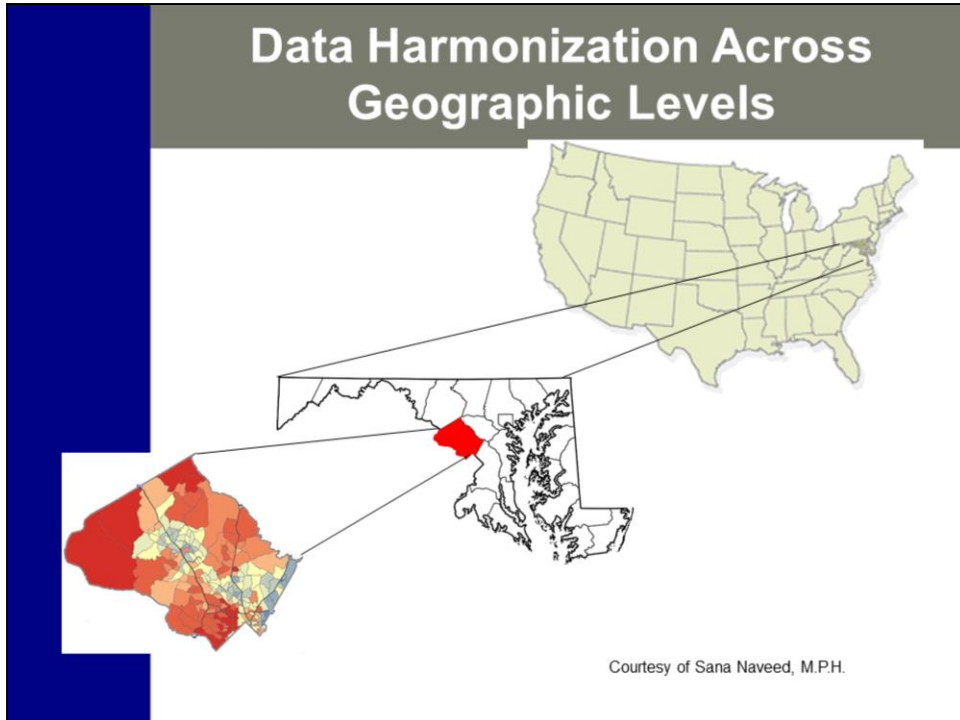
- **Statistical analysis of a single dataset that consists of two or more separate samples**
- **Different than meta-analysis**
- **Independent of data content or focus**

- **Summaries of Bayesian BRFSS-alone and BRFSS/NHIS county-level estimates of prevalence rates for current smoking among adult males in 2000, by range of telephone non-coverage rates (based on work described in Raghunathan et al. 2007)**

Range of Telephone Non-Coverage Rates (%)	Mean of County-Level Estimates (%)	
	BRFSS-Alone	BRFSS/NHIS
< 2	20.6	20.4
2 – 3	21.1	23.0
3 – 5	21.9	24.3
5 – 8	23.0	25.7
8 – 10	24.1	26.6
10 – 15	24.4	27.7
15 – 20	25.4	29.8
≥ 20	24.1	30.8

Courtesy of Nathaniel Schenker, NCHS

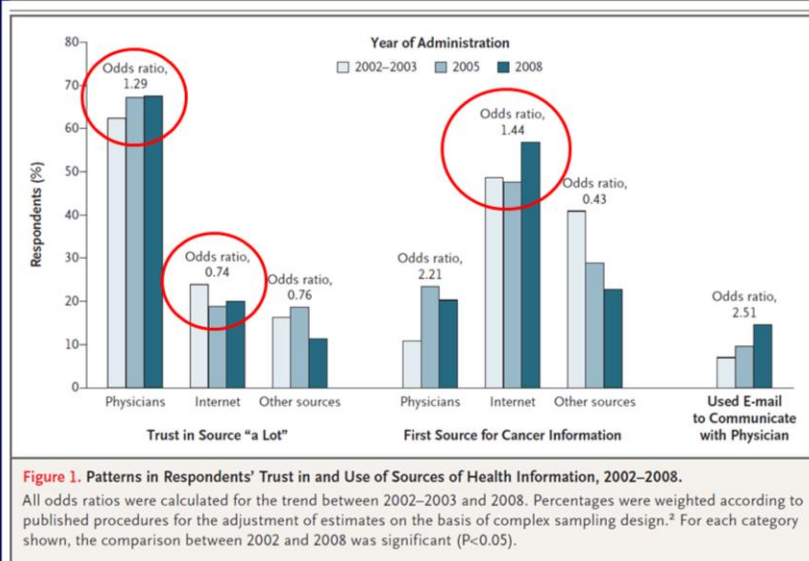
Data Harmonization Across Geographic Levels



Graphic: Picture of the United States, the state of Maryland, and Montgomery County in Maryland, demonstrating how using harmonized data data allows researchers to compare results across geographic levels from the local, state and national levels, in addition to regions.

Using harmonized data facilitates comparable local, state, and national data.

Allows for Trend Analyses



Hesse, B. W., Moser, R. P., & Rutten, L. J. (2010). Surveys of physicians and electronic health information. *NEJM*, 362, 859-860.

Graphic: A set of bar charts comparing HINTS data over 3 iterations. Having the same items across survey iterations allows for trend analysis to **test for differences in outcomes over multiple iterations of cross-sectional survey data.**

Briefly, data across three administrations of HINTS was analyzed to gain a better understanding of the public's trust and use of sources of health information,

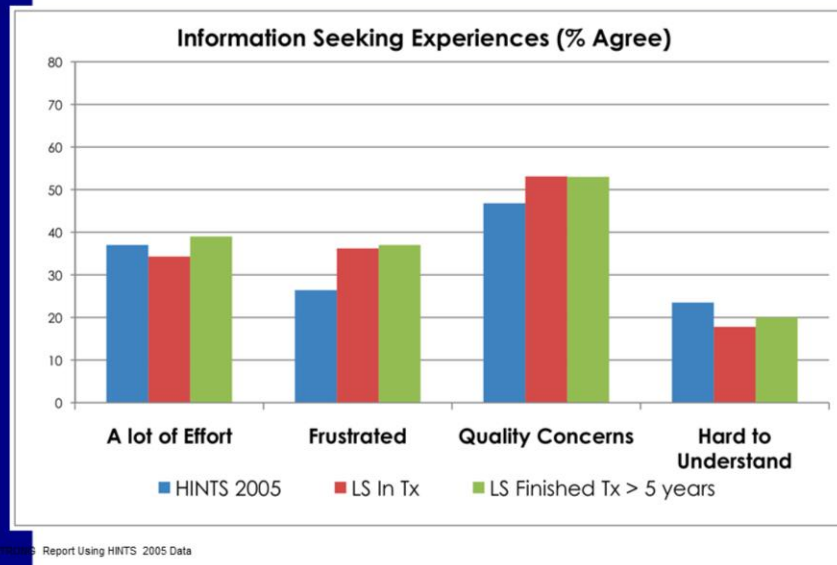
particularly from physicians, the internet, and other sources, such as the mass media.

From this graph, we can see that, overtime, while a larger percentage of respondents reported using the internet as their first source for cancer information, trust in health information from the internet decreased.

Additionally, despite a decade's worth of exposure to health information on the Internet, the public's trust in physicians as their preferred source of health

information increased from 2002 to 2008.

Comparisons Across Studies



Graphic: A set of bar charts comparing HINTS data with those gathered by LIVESTRONG, a cancer advocacy group.

LIVESTRONG did a survey with cancer survivors and combined with NCI's Health Information National Trends Survey (HINTS)

LIVESTRONG decided to **add a few of the same items from HINTS to their own survey of cancer survivors.**

As a result, LIVESTRONG is now able to make comparisons of important outcomes (e.g., what percentage of respondents have looked for health information?) across the two populations of interest.

Health Information National Trends Survey (HINTS) is a health survey of the general adult US population administered by the National Cancer Institute that assesses the communication needs of the respondents.

The Future of Health Survey Design

- **Collaboration/Coordination**
 - Doing more with less
 - Identify redundancies or gaps
 - Data linkages
- **Data Harmonization**
 - Creating/using shared standards
 - A priori vs. post-hoc
 - Decreased costs
 - Build a cumulative science
- **Empowering Communities**
 - Use of standards by local communities
 - Engaging survey consumers
 - Data and results users



22

MY OPINIONS—THESE DO NOT NECESSARILY REPRESENT THOSE OF THE NATIONAL CANCER INSTITUTE

There is also a sense that in the Federal government surveillance system we can do more with what we have. Conducting more surveys does not seem to be the answer. Conducting better surveys in a systematic and coordinated fashion does. This means creating agreed-upon health indicators and outcomes that can be shared and used by others. If this can be accomplished more readily, the ability to compare across data collection systems will be enhanced (Institute of Medicine, 2010).

It also means systematic planning across data collection systems to avoid duplication of efforts, or just as importantly, identify gaps that need to be filled. This can decrease costs, increase efficiency and allow researchers to learn and build off each others' work, that is, build a cumulative science. The overall idea is that if researchers can agree *a priori* on which measures to use in their research, the ability to share resulting harmonized data and build a cumulative science increases.

HINTS-GEM was built to increase the HINTS Program's commitment to and enablement of measure sharing and data harmonization. The results presented here suggest that the NCI achieved success at several levels through use of HINTS-GEM. Not only did the number of researchers who engaged in the HINTS development process greatly increase over years past, but the amount of new content proposed, as well as consensus regarding existing HINTS content, increased as well. Additionally, the more than 100 HINTS-GEM users who engaged in the process of building the HINTS 4 item pool are now in a position to use the consensus-driven Measures found in HINTS-GEM in their own research, thus allowing for harmonization between local and national surveillance efforts.

The HINTS Program has already engaged in this sort of partnership: in 2009, the NCI partnered with the University of Puerto Rico to field a HINTS survey in the US territory of Puerto Rico. Because there was a conscious effort to reuse the same items from a previous HINTS survey—in this case the 2008 effort—there now exists ways of making direct comparisons between outcomes between the two surveys and associated geographic areas. The development of similar partnerships is currently underway, and these future efforts will be able to make use of the HINTS-GEM infrastructure to increase the efficiency and effectiveness of these endeavors.

There are several next steps for using HINTS-GEM. The site will be used to solicit further input to build consensus around the items that are selected for the Cycle 1, 2, 3, and 4 HINTS 4 instruments. HINTS-GEM will also be used to communicate with the HINTS community about final item selections so that researchers can field local HINTS data collections in concert with the national-level data collection if they so choose. Finally, when HINTS 4 data are collected, the data will be made publicly available on HINTS-GEM, with the opportunity for researchers to share their own local HINTS data collections via the site.