# Open Government and the National Institutes of Health: Crowdsourcing the Research Enterprise

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U.S. DEPARTMENT DF HEALTH AND HUMAN SERVICES



# **The National Cancer Institute**





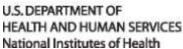
U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES National Institutes of Health

**NCI** was established by congress in 1937, is the leading Federal agency and world's largest organization solely dedicated to cancer-related research, training, and dissemination of information. **DCCPS** aims to reduce the risk, incidence, and deaths from cancer as well as enhance the quality of life for cancer survivors.

- Cancer = an incredibly diverse, complex set of diseases
- 500,000+ cancer-related deaths estimated to occur in 2011
- ≈50% of cancer related deaths can be attributed to preventable behaviors and exposures (tobacco, diet, phys. activity, screening,...)
- 1% reduction in cancer deaths = \$400+ billion in savings

# The National Cancer Institute





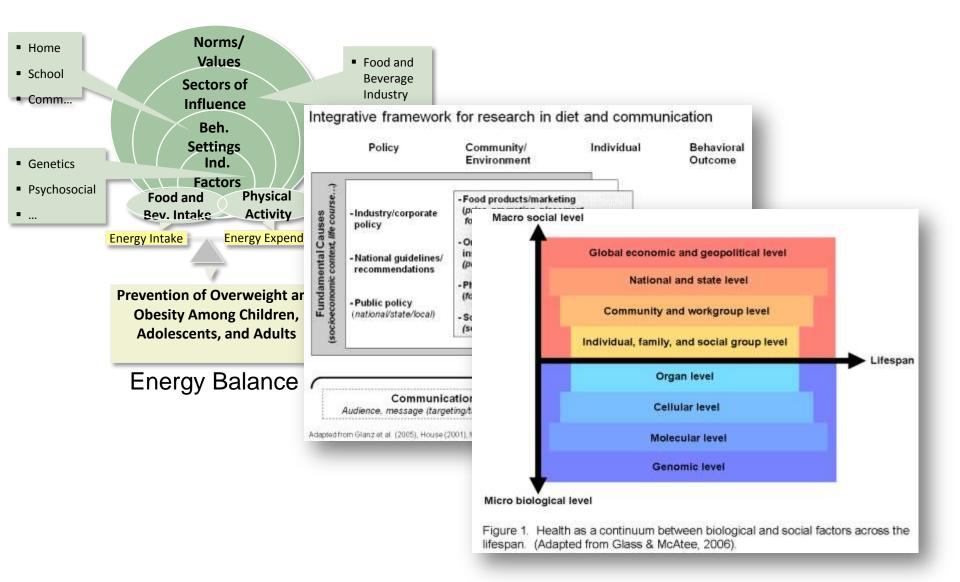


**Cancer Control Framework** 



Reducing the cancer burden

# What is Population Science?

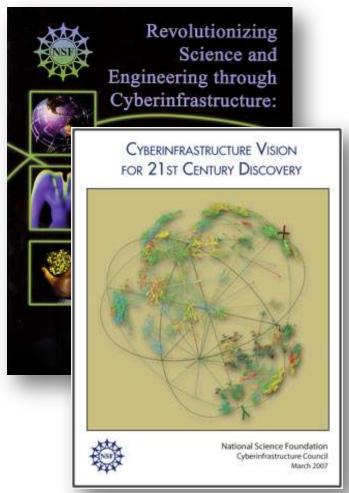


# In this age of 'Big Data'...

...a grand experiment is unfolding on the utilization of data for public health impact.



# The National Science Foundation



The Atkins Report (2003) & CDI (2007)

"...five-year initiative to create revolutionary science and engineering research outcomes made possible by innovations and advances in computational thinking."

- From Data to Knowledge
- Understanding Complexity
- Virtual Organizations

# Institute of Medicine and the National Academies of Science

Computational Technology for Effective Health Care (2009)

The Learning Healthcare System (2007)

Crossing the Quality Chasm (2001)

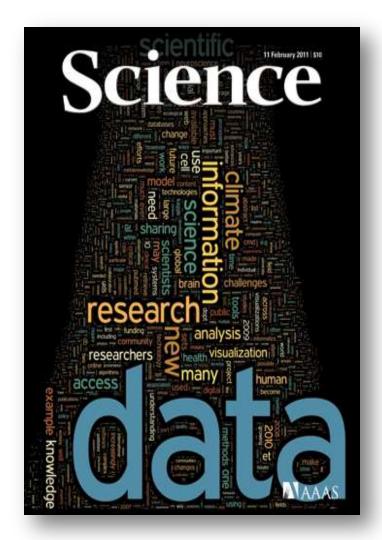
The digital information revolution = the "structural inability" of health practitioners to exploit the unprecedented amount of electronic health-related information that now lies at our fingertips.

- Institute of Medicine



THELFARNING

# Science (Feb. 11, 2011)



#### **Gary King** (Harvard)

Social scientists need to continue to build a common, open-source, collaborative infrastructure that makes data sharing & analysis easy.

#### Peter Fox & James Hendler (RPI)

Visualization is not the end product of scientific analysis, but an **exploration tool** for hypothesis development in the continually more data-intensive scientific process

Challenge of modeling integrated data is exponentially harder = systems-level perspectives & transdisciplinary science

# PCAST - "Designing a Digital Future: Federally Funded R&D in NIT" (Dec. 2010)

- I. "Every Federal agency needs to have a BIG DATA strategy"
- II. "Improvements in health & QOL...depend upon knowledge and information that can drive appropriate actions"
  - Comprehensive 'life long' individual health records
  - From data to knowledge for empowering health (scalable architecture)
  - Tools & apps for **personalized healthcare**
- III. "Democratization of research & education"

#### IV. HHS & NSF collaboration:

- Data sharing & computation
- Environment and sensor data (contextualization)
- HCI and 'human-NIT' interactions



#### Conceptual Framework for Cyberinfrastructure for Consumer Health

(Shaikh, Prabhu Das, Vinson, Spring, 2011)

# Information Ecology

# Established Data Sources

- Surveillance
- Research
- Administrative
- Medical
- Biological
- Genomic/proteomic
- Census
- Policy...

# **Emerging Data Platforms**

- EHRs/PHRs
- Mobile devices
- Sensors & GIS
- Data.gov
- Web 2.0 (blogs/ microblogs/wikis, video/photos, social networks, PHRs,...)...

#### Cyberinfrastructure

(Grid and Cloud Computing)

# **Applications for Population Health**







Common
Vocabularies &
Middleware







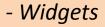






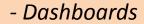












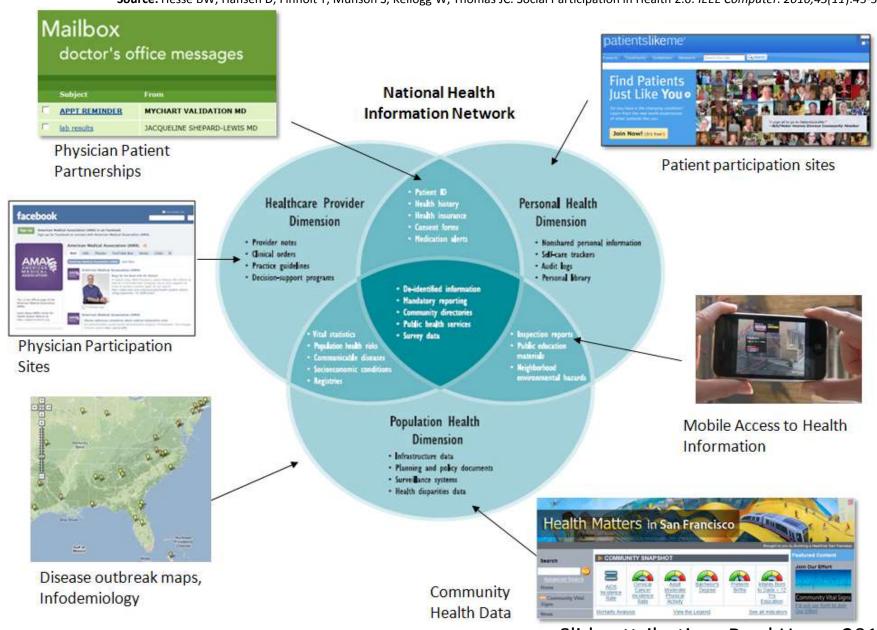
- Medical devices & technologies...

keas





The Research Landscape
Source: Hesse BW, Hansen D, Finholt T, Munson S, Kellogg W, Thomas JC. Social Participation in Health 2.0. IEEE Computer. 2010;43(11):45-52.



Slide attribution: Brad Hesse 2010

#### Bench to Bedside...

Abroms et al. (2011). iPhone Apps for Smoking Cessation: A content analysis. *American Journal of Preventive Medicine*, 40 (30), 279-85.

- Apps rarely adhere to established guidelines for smoking cessation (e.g., pharmacotherapy, quit lines, counseling).
- Similar findings in other health-related/preventive behaviors
- NCI K-award (CA124579)

= GAPs in translating science and disseminating for impact

# 2010 NCI Developer Challenge



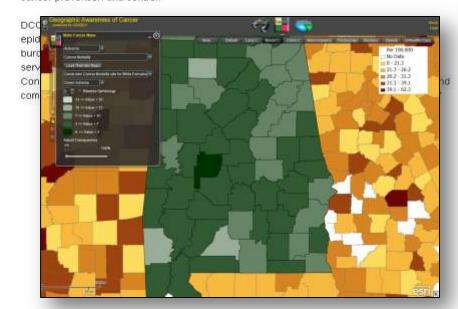


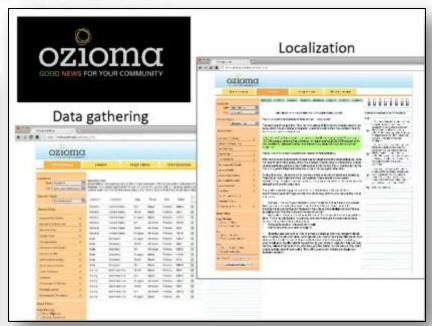
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About Challenges Teams People Resources LIVE CODE! Partners Sponsor Gallery In the News Blog

#### **Enabling Community Use of Data for Cancer Prevention and Control**

Using data available through the National Cancer Institute's (NCI) Division of Cancer Control and Population Sciences (DCCPS) and their partners, develop prototype web and/or mobile communication technology applications to enable communities' use of population data for cancer prevention and control.





#### **Initial Outcomes**

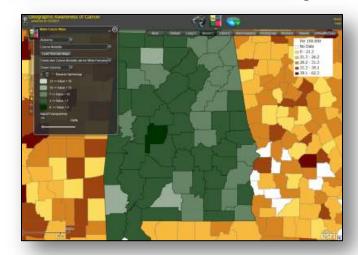
Caburnay et al. (Washington University):
OZIOMA provides locally-relevant cancer data
and statistics, resources, and graphics for
media and PR professionals

- Aggregates multiple data sources (SEER, HINTS, BRFSS...) to enhance the relevancy of health related news stories
- NCI Centers grantee (CA-P50-95815)

**GSAREH (Austin, TX):** data visualization and multi-level GIS mapping app



LocalHealthData.org



#### America COMPETES Act

#### Dec 21, 2010: Act is re-authorized

Congress grants authority to all Federal agencies to use prizes/challenges to

- Spur innovation
- Solve difficult problems
- Advance core missions



**Challenge.gov** = central platform for crowdsourcing Govt. competitions for open innovation

WHEALTH.DATA.GOV

**ONC Investing in Innovations (i2)** = collaborate with HHS agencies to further agency missions, pay only for results, increase diversity of entities addressing challenges, and stimulate private sector investment,

#### June 9 Health Data Initiative Forum

# The Health Data Initiative: Turning HHS and our sister agencies into the "NOAA of health data"

**FUELS** 

#### Health-related data from











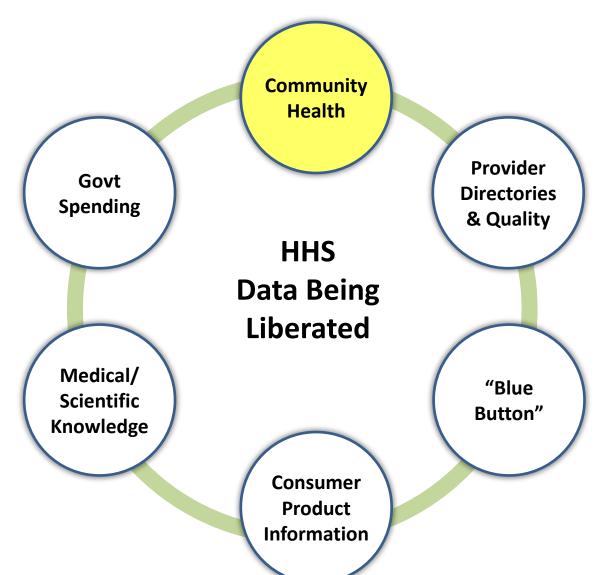
Made available to the public

#### **A Rapidly Growing Array of Innovative Products and Services That:**

- Help consumers take control of their health and health care
- Help employers promote health and wellness
- Help care providers deliver better care
- Help journalists shed light
- Help local leaders make betterinformed decisions
- Support all of the above through "data intermediary" services
- And much more

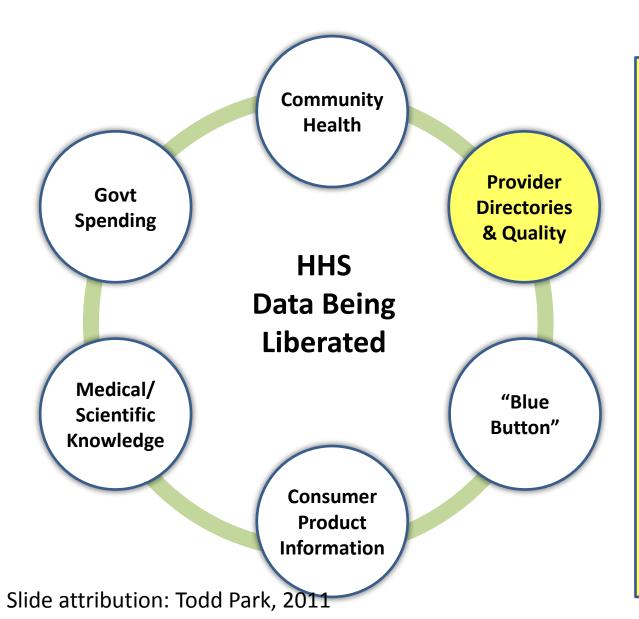
# Health Data Initiative core activities: liberate data and catalyze innovation

- **1. Publish brand new HHS data for public access** while rigorously protecting privacy and confidentiality
- 2. Make existing HHS data much more accessible -- "machine-readable," downloadable, accessible via application programming interfaces (APIs), free, much easier to find
- 3. Energetically publicize our data to innovators -- who can use it as raw material to develop applications and services that help improve health and health care



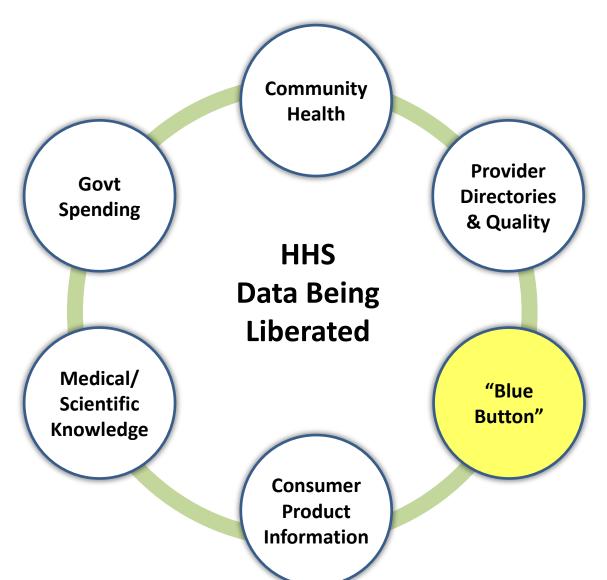
# **Community Health Data Example:**

- Health Indicators
   Warehouse, at healthindicators.gov
- 1,170 metrics of community health and health care performance
- Launched 2/2011



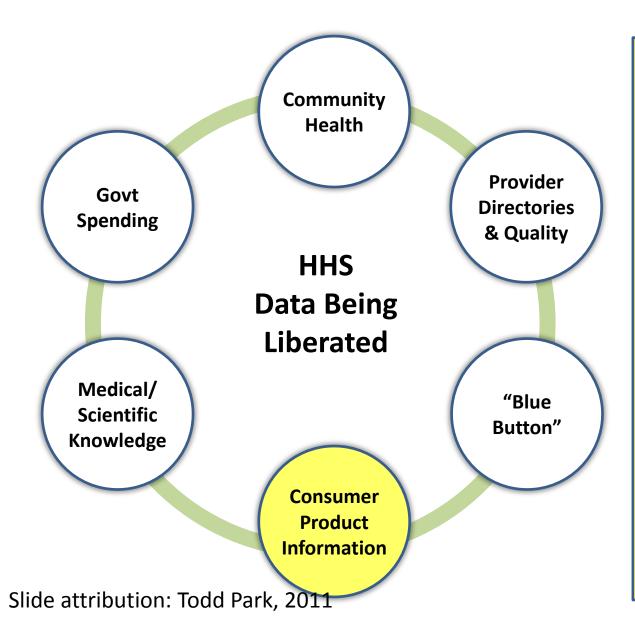
# **Provider Directories &**Quality Data Examples:

- Nationwide directories of care providers
- Provider quality COMPARE APIs at data.medicare.gov, launched 9/2010
- Medicare claim files for provider quality measurement, coming 1/2012



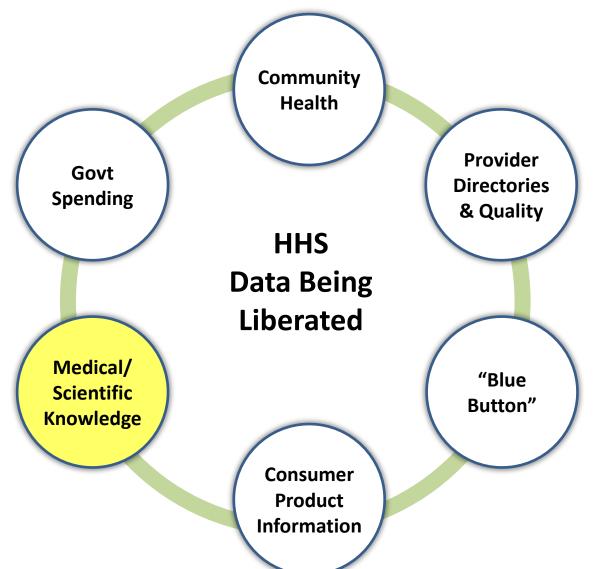
#### "Blue Button" Data

- VA, HHS, DoD joint venture
- Allows veterans,
   Medicare
   beneficiaries, and
   active duty military
   to download their
   own claims or
   personal health
   information
- Launched 10/2010



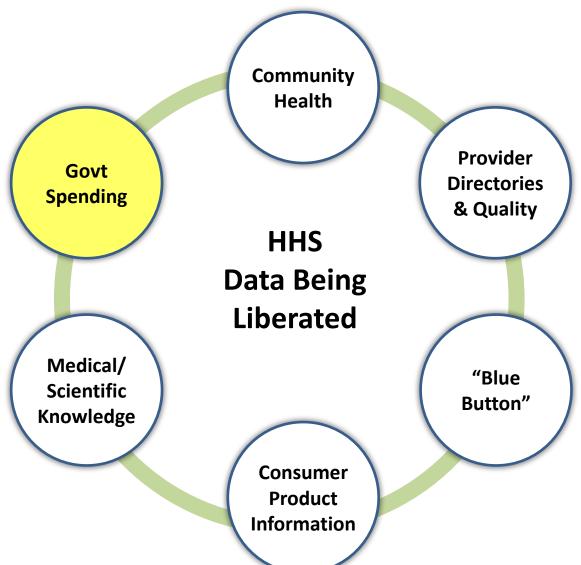
# **Consumer Product Information Examples:**

- FDA recall (drugs, devices, food) data in downloadable XML format --published 10/2010
- Health insurance products available in the individual and small business markets across the U.S. – made available via downloadable files 8/2011



#### Medical/Scientific Knowledge Examples:

- National Library of Medicine API Portal, deployed 9/2010, including ClinicalTrials.gov and Pillbox APIs
- Medline Plus
   Connect, launched
   11/2010



# **Govt Spending Data Example:**

Medicare claims
 "basic standalone
 files" – first-ever
 claim-level files
 ("slimmed" for
 privacy protection),
 available for free
 public download for
 all major types of
 care as of 5/2011

# Bringing it all together: Health.Data.gov, the one-stop place to get all of our free, publicly available data (launched 2/2011)



#### Publicizing our data to innovators across America

- Challenges and "code-a-thons" (Health2Challenge.org, Challenge.gov)
- Many innovator "meetups" and conferences



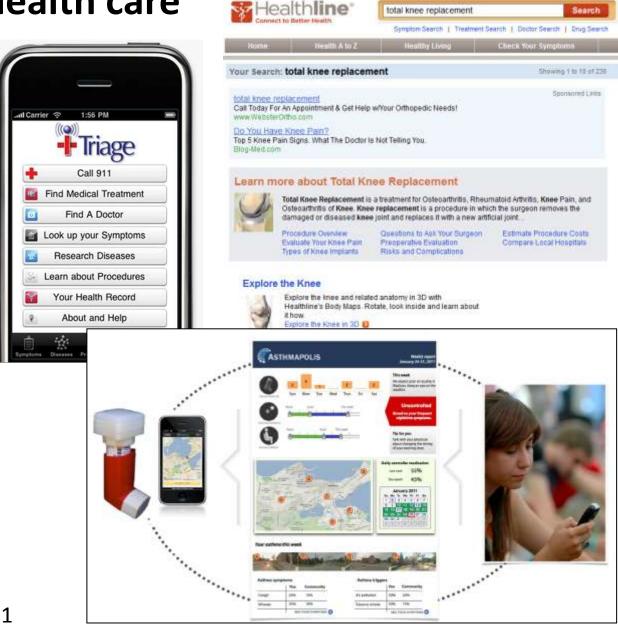
#### The June 9, 2011 Health Data Initiative Forum

- 2<sup>nd</sup> annual "health datapalooza" -sponsored by the Institute of Medicine and HHS
- Showcased 50 of the best innovations developed by companies that help consumers, care providers, employers, and communities improve health and health care
- Featured major announcements by nearly 20 additional companies and other organizations



Examples: helping consumers take control of their health and health care

- iTriage
- Healthline
- Castlight
- Patients Like Me
- Asthmapolis
- Food Oasis



# Examples: helping care providers deliver better care (and succeed as accountable delivery systems)

- Aetna
- Essence Group/Lumeris
- Doximity
- Press Ganey
- Rise Health
- ElizaLIVE



## **Examples: helping communities improve health**

- Ozioma
- ESRI
- Network of Care for Healthy Communities
- Palantir/CDC







#### Selected announcements at the Forum

- Walgreens 2.0 + challenge
- Aetna Foundation challenge
- Sanofi Aventis diabetes challenge
- NCIIA Nursing Home of the Future "invent-a-thon"
- University of Michigan: nation's first consumer health informatics masters degree program
- Startup Health: new health startup "seed accelerator/entrepreneurship academy"
- New "Health Data Consortium"









#### Founding members of the Health Data Consortium

- Academy Health
- California HealthCare Foundation
- Consumers Union
- ESRI
- Gallup-Healthways Well-Being Index
- Grantmakers in Health
- Health 2.0
- InnoCentive
- Institute of Medicine
- Lucile Packard Foundation for Children's Health
- Mayo Clinic Center for Innovation
- National Association of Counties
- O'Reilly Media
- Robert Wood Johnson Foundation
- U.S. Department of Health and Human Services



## **Key Next Steps for the Health Data Initiative**

- With the support of the new Health Data Consortium, continued campaign to connect innovators to our data
  - Challenges and "code-a-thons"
  - -- Innovator "meetups"
  - -- More roving "health data evangelists"
  - -- 2012 Health Data Initiative Forum
- Launch of semi-annual data reviews and brainstorming sessions with each HHS agency
  - Data access improvements made over the past 6 months and planned over the following 6 months
  - Brainstorming about how we can connect innovators to each agency's data to help advance their mission
  - -- Expansion to include "semi-open" data

NCI's Challenge Team



The Office of the National Coordinator for Health Information Technology









**NCI**: Abdul Shaikh, Glen Morgan, Lila Rutten, Paul Courtney, James McClain, Gordon Willis, Bob Wagner, Zaria Tatalovich, Patti Weber, Sana Naveed, Amy Sanders, Heather Edwards, Brad Hesse

**ONC**: Wil Yu, Adam Wong

**CGU**: Tom Horan, Sue Feldman

U. Hawaii: Bill Chismar

RPI: Deborah McGuinness et al.

Northwestern: Noshir Contractor et al.

Health 2.0: JL Neptune, Lizzie Dunklee, LeAnna Carey, Indu Subaiya, Matt Holt

# **2011 NCI/ONC Challenge:** *Using Public Data for Cancer Prevention and Control: From Innovation to Impact*

Encourage development of innovative apps that:

- 1. Use **public data** relevant to cancer
- 2. Have the potential to integrate with existing technology platform(s)
- 3. Addressing challenges faced by consumers, clinicians, or researchers at one or more points on the **cancer control continuum**

#### THE CANCER CONTROL CONTINUUM

#### PREVENTION

Tobacco control
Diet
Physical activity
Sun exposure
Virus exposure
Alcohol use
Chemoprevention

#### DETECTION

Pap test Mammography FOBT Sigmoidoscopy PSA

#### FOCUS DIAGNOSIS

Informed decisionmaking

#### TREATMENT

Health services and outcomes research

#### SURVIVORSHIP

Coping Health promotion for survivors

Multi-level peer support, consumers/clinicians, information, monitoring

Decision support, care coordination, collaboration

Follow-up and decision support, care coordination, patient engagement

confination, collaboration, reminder systems

Transition to 1°, surveillance, health promotion, end-of-life



# **Key Dates**

Phase I: 4 semi-finalists each receive \$10,000 at Health 2.0



#### Phase II:

Final submissions due Nov. 18 2011

Winners notified: Nov. 30th 2011

**Awards Presentation:** 2 winners each receive \$20,000 at HICSS Symposium Jan. 4th, 2012

#### **Judges**









Jessie Gruman, Mike Gillam, Center for Advancing Health

Microsoft

Adam Clark, **FasterCures** 

Vic Strecher, University of Michigan

## NCI Investments in HIT, Innovation, and Population Science

- Journals & Knowledge Products (AJPM, TBM)
- PopSciGrid Community Health Data Portal (proof of concept for data harmonization and visualization)
- **GEM & HINTS-GEM** (Grid-Enabled Measures Platform)
- Informatics for Consumer Health
- CECCRs (e.g., RCT for web-tailored smoking cessation;
   EMR promotes screening adherence)
- Funding Opportunities







### Recent NCI Knowledge Products: Cyberinfrastructure, data liquidity & systems science



Shaikh, A.R., Prabhu Das, I., Vinson, C., Spring, B. (eds.). **Cyberinfrastructure for Consumer Health**. American Journal of Preventive Medicine, 2011: 40(5).

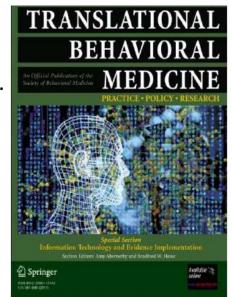
Making Sense of the Data Explosion: The Promise of Systems Science (Mabry)

Infodemiology and Infoveillance: Tracking Online Health
Information and Cyberbehavior for Public Health (Eysenbach)

Abernethy, A., Hesse, B., Spring, B (eds.). **Information Technology and Evidence Implementation. Translational Behavioral Medicine**, 2011: 1(1).

Supporting implementation of evidence-based behavioral interventions: the role of data liquidity in facilitating translational behavioral medicine (Abernethy et al.)

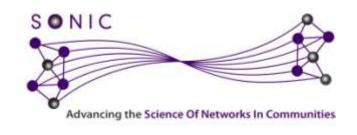
CYberinfrastructure for COmparative effectiveness REsearch (CYCORE): improving data from cancer clinical trials (*Patrick et al.*)



# PopSciGrid Community Health Data Portal: A proof of concept & exploratory tool









Tetherless World Constellation Linked Open Government Data Portal nd User Portal Applications Fast, low-cost mashups built Semantic Web in Gov Domain w CS AND domain experts US, UK, China. Major partner of Data gov 3 8.6 billion triples in LOO Health, energy, economic The New Hork Eimes DATAGOV TWC LOGD Query Access - DES

http://logd.tw.rpi.edu/project/popscigrid

http://cancercontrol.cancer.gov/hcirb/cyberinfrastructure/popsci.html



**Smoking prevalence:** Percentage US adults who currently smoke (BRFSS 1991-2007) \*\*

**Smoke free bars (%)**: Percentage of population affected by the smoke-free policy for bars \*

**Smoke free workplace (%)**: Percentage of population affected by the smoke-free policy for workplaces \*

**Smoke free restaurant (%)**: Percent of population affected by the smoke-free policy for restaurants \*

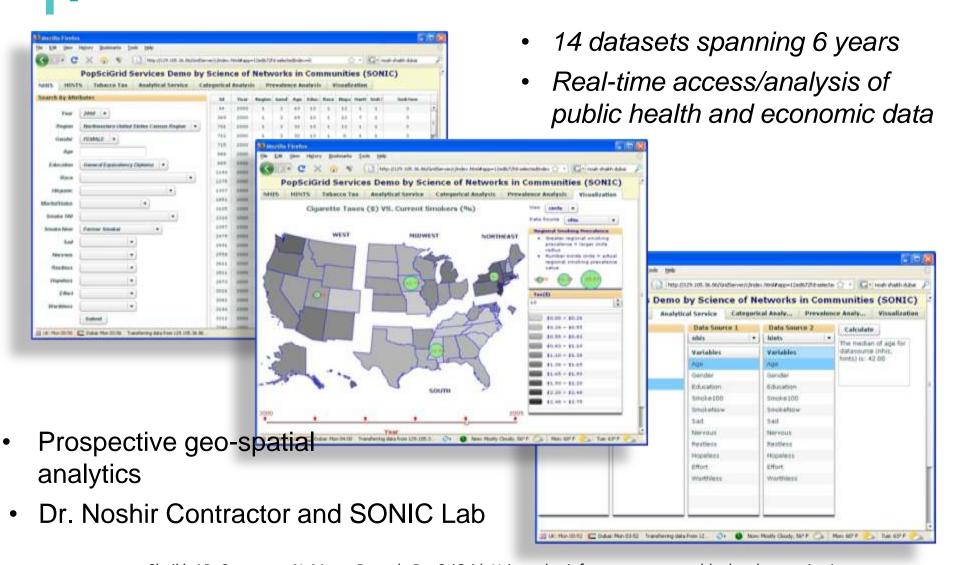
**Price per pack in dollars (\$)**: Average price per pack of cigarettes adjusted for inflation (1991 dollars) \*\*

**Tax per pack in dollars (\$)**: State excise tax per pack of cigarettes adjusted for inflation (1991 dollars) \*\*

<sup>\*</sup> Tatalovich, Mariotto, Hunt, Howlader, Marcus & Stinchcomb. "Reconstructing the spatio-temporal patterns of tobacco policy coverage in the United States" (forthcoming)

<sup>\*\*</sup> http://www.impacteen.org/tobaccodata.htm

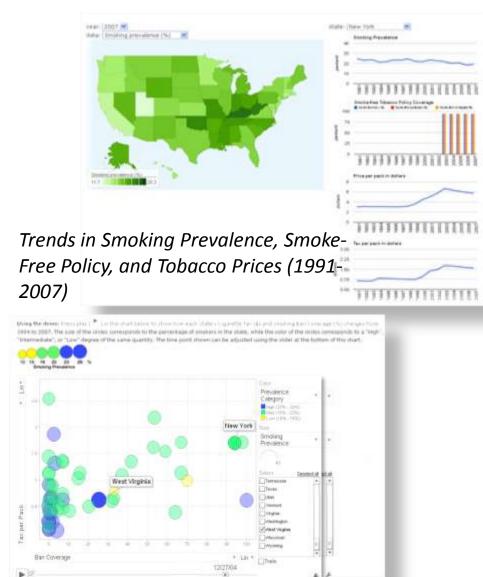
### PopSciGrid Original Proof of Concept



Shaikh AR, Contractor N, Moser R, et al.. PopSciGrid: Using cyberinfrastructure to enable data harmonization, collaboration, and advanced computation of nationally representative data. American Public Health Association Annual Meeting; November 11, 2009; Philadelphia, PA.

### NCI's PopSciGrid Community Health Data Portal – An Exploratory Tool

- Builds on the original PopSciGrid proof of concept (2007) for data sharing, collaboration, communication.
- Exploratory tool for:
  - Health science: communicating health info online, policies (taxation, smoking bans, etc) impacting health; visualizing complex data; support cancer prevention and control
  - Computer science: use semantic technologies, tools to enable developers/public to build demos and interpret data, facilitate collaboration and make applications 'go viral.'





www.gem-beta.org - A grid-enabled, interoperable, dynamic website for behavioral and social science theoretical constructs and measures





#### Health Information National Trends Survey

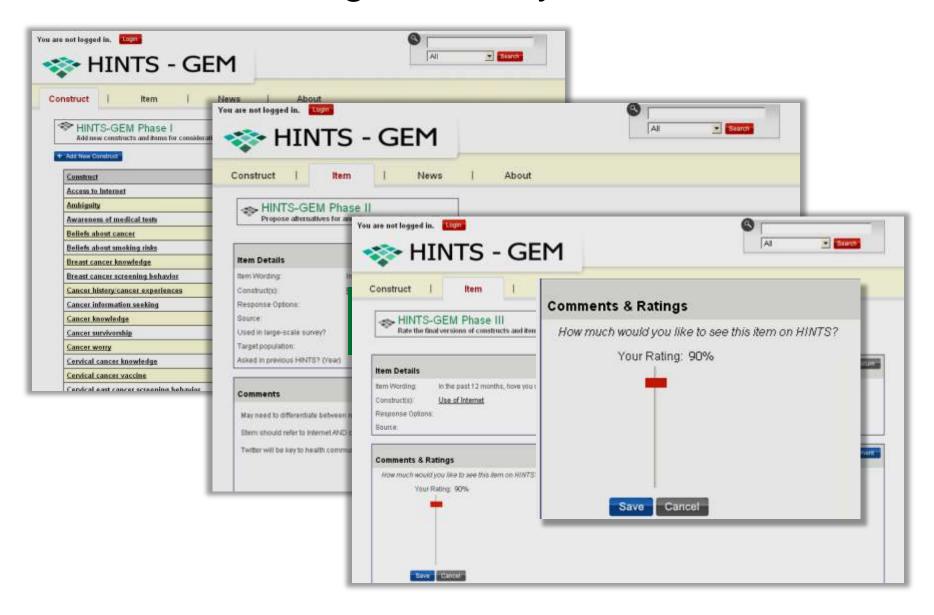
How Americans find and use cancer information

#### **HINTS-GEM**

Engage the public in content generation for the next iteration of HINTS.

- Participants have the opportunity to submit content for consideration, rate, and comment on content proposed by other participants and by NCI.
- HINTS-GEM also serves as a vehicle to keep the public updated on the survey process during the modular roll-out of the next iteration of HINTS.

### HINTS-GEM: Using Science 2.0 for Public Solicitation/Vetting of Survey Items



#### **Informatics** for **Consumer Health**

InformaticsForConsumerHealth.org

Empowering providers and consumers to manage health care



Sign up for our monthly Alert Service sent directly to your inbox



#### InformaticsForConsumerHealth.org is a federally supported initiative that:

- Serves as a clearinghouse of knowledge for use in the development of high-quality evidence based products for integration into the Nationwide Health Information Network
- Creates an interactive portal where all stakeholders can exchange ideas and information about available resources, projects, opportunities, and partnerships
- Provides a platform for conversation and collaboration around informatics for consumer health

#### Log on to this valuable resource to access:

- . The most current web articles from leading media outlets
- A comprehensive, searchable database of peer-reviewed literature
- A calendar of upcoming meetings, workshops, and conferences
- · Funding and collaborative opportunities, and
- The ICH Blog, featuring expert guest bloggers

















#### **Previous NIH FOAs**

PA-08-239: Impact of Health Communication Strategies on Dietary Behaviors (R01, R21)

NCI Program Contact: Tanya Agurs-Collins (collinsta@mail.nih.gov)





Integrative framework for research in diet and communication

NIH Challenge Grant 10-CA-101:
Cyberinfrastructure for Health: Building
Technologies to Support Data Coordination
and Computational Thinking

SBIR FY2010 Topic: Data Harmonization and Advanced Computation of Population Health Data



#### **Current NIH FOAs**

#### PAR 10-145: Social Network Analysis and Health (R01)

- e.g., theories, interactions & processes, health behaviors, methodologies & technologies
- PA-11-238: Spatial Uncertainty: Data, Modeling, & Communication (R01, R21, R03)
- e.g., development of visualization techniques that communicate about uncertainty in people's environmental exposure patterns and association b/t disease and environmental exposure
- PA-11-063: Translating Basic Behavioral and Social Science Discoveries (R01)
- e.g., network analyses, systems dynamics approaches for systems-level interventions for healthy behaviors (how/when/where interventions should target systems for benefit)
- Also see Patty Mabry's resource list (NIH OBSSR):

  <a href="http://obssr.od.nih.gov/scientific areas/methodology/systems science/Funding">http://obssr.od.nih.gov/scientific areas/methodology/systems science/Funding</a>

opportunity Announcements in systems science August 2011.pdf

#### **Strategic Research Questions**

What are the social psychological principles that will best guide development of "technology-mediated social participation (TMSP)" systems in cancer control?"

[source: Kraut R, Maher ML, Olson J, Malone TW, Pirolli P, Thomas JC. Scientific Foundations: A Case for Technology Mediated Social Participation Theory. *IEEE Computer.* 2010;43(11):22-28.]

What are the innovations in *information visualization* needed to communicate data effectively to practitioners and patients in high throughput data environments?

[source: Nelson DE, Hesse BW, Croyle RT. Making Data Talk: Communicating Health Data to the Public, Policy, and the Press. New York, NY: Oxford; 2009 (see Chapter 8)]

How can the "always-on, always proximal" interfaces of mobile devices be used to engage individuals: (a) in healthy behaviors and (b) in participatory science?

[source: Fox S. Cancer 2.0: A Summary of Recent Research. Washington, DC: Pew Research Center; 2010. Report presented to the President's Cancer Panel, December 14, 2010)].

#### **Looking Ahead in Open Innovation and Data**

- Continue building ecology of developers, entrepreneurs, scientists with publicprivate partnerships (e.g., Health Data Consortium, HICSS, challenges)
- Work with NCI SBIR Development Center to fund innovative, evidence-based apps
  - Commercializing HIT for consumer and clinical health outcomes; potential Phase II fast track; encourage small and large business collaboration;

CROWDSOURCING

- Expand NIH Crowdsourcing and Open Innovation efforts (e.g., July 18<sup>th</sup> mtg with Tim O'Reilly, Karim Lakhani,...)
  - HHS.gov challenge platform:
     http://www.hhs.gov/open/initiatives/challenges/index.html
- Inter-agency and public-private collaborations.
  - US Ignite White House OSTP and NSF next-generation, gigabit/advanced technology network applications
  - 2013: NIH-NSF joint solicitation for Big Data and Health USIGNITE
  - Encouraging multi-disciplinary applicants to apply for NIH/NCI funding