

Radical Collaboration: The Science of CrowdSourcing and CrowdSourcing Science

Presentation to the Government-University-Industry
Research Roundtable

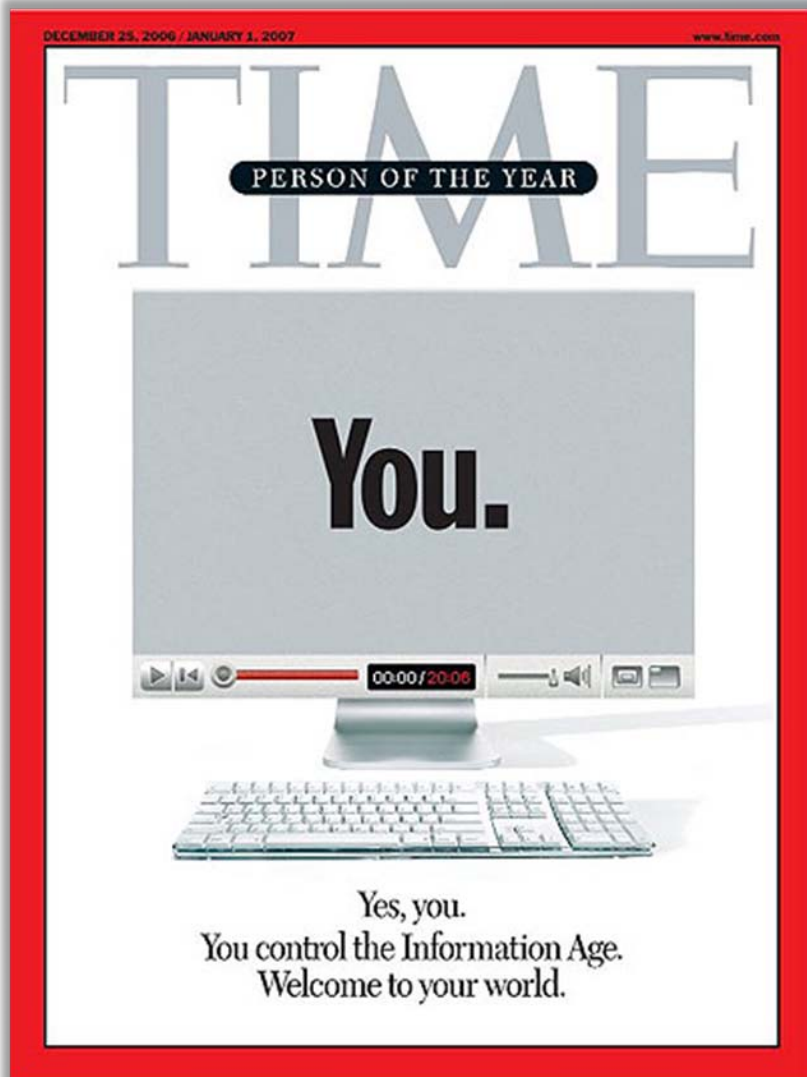
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October 5, 2011

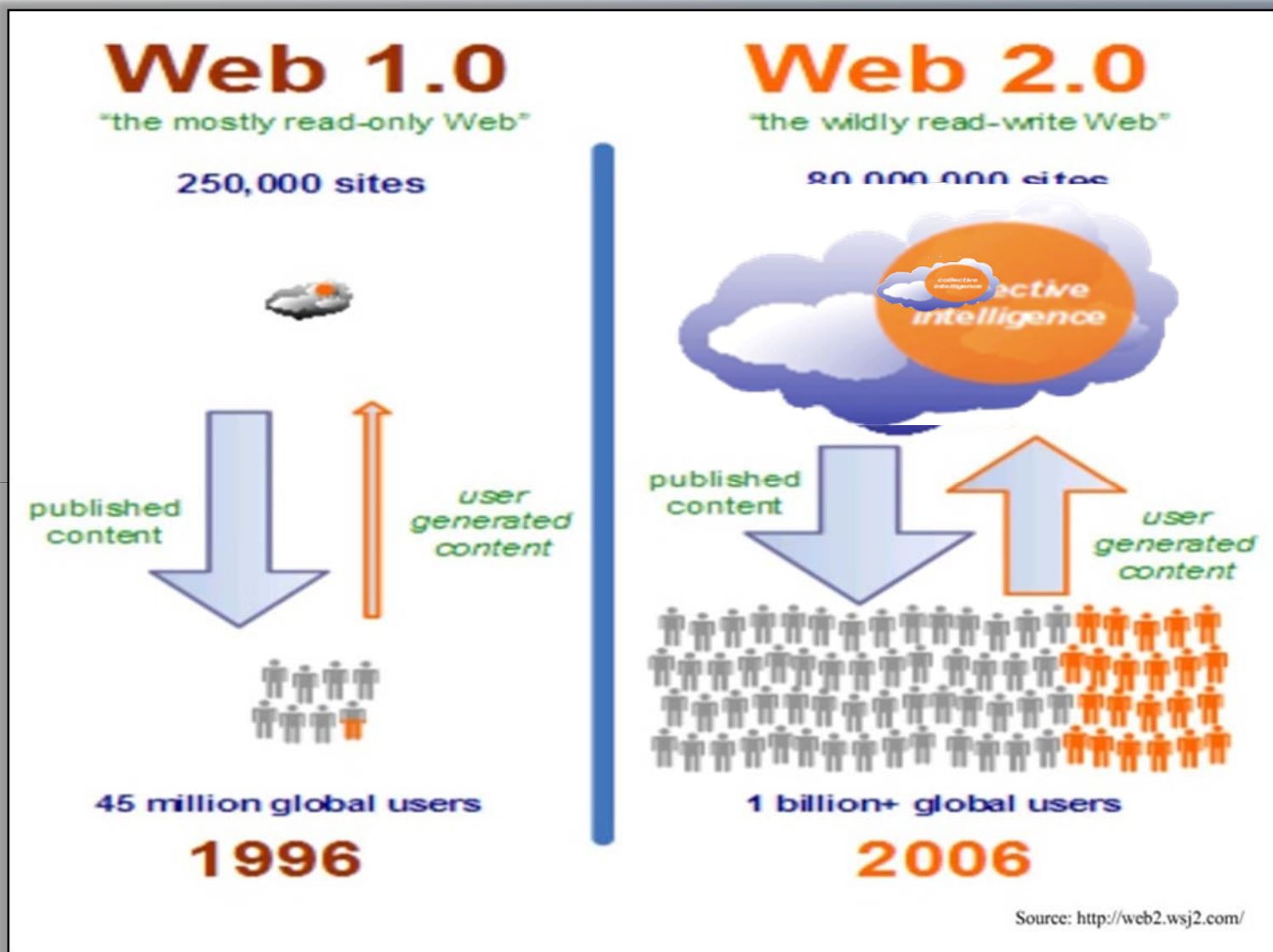
Emergence of the Participative Web



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

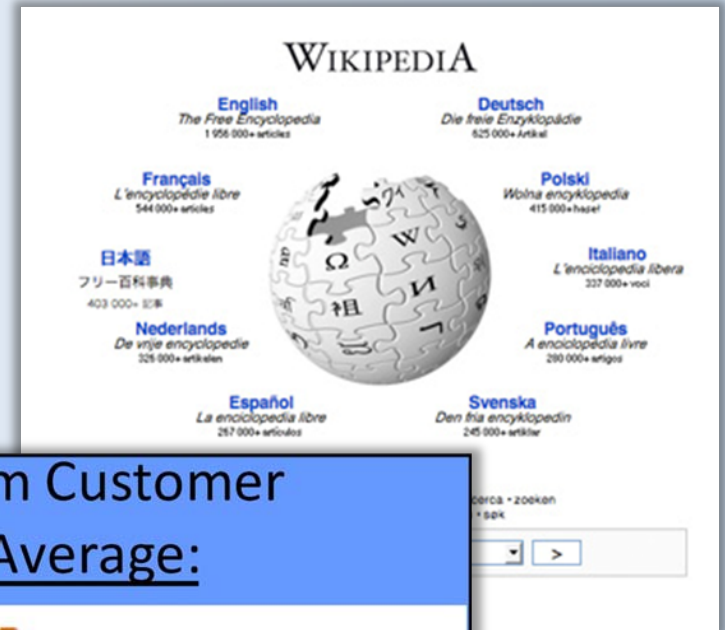
Time Magazine, 2006

Evolution of The Internet



Courtesy of Gunther Eysenbach, "Infodemiology & Infoveillance," slideshare.net

Science in a New Collaborative Environment



Amazon.com Customer Review Average:

Customer Reviews Monster Hunter Tri

49 Reviews

5 star:	<div><div></div></div>	(32)
4 star:	<div><div></div></div>	(12)
3 star:	<div><div></div></div>	(4)
2 star:	<div><div></div></div>	(0)
1 star:	<div><div></div></div>	(1)

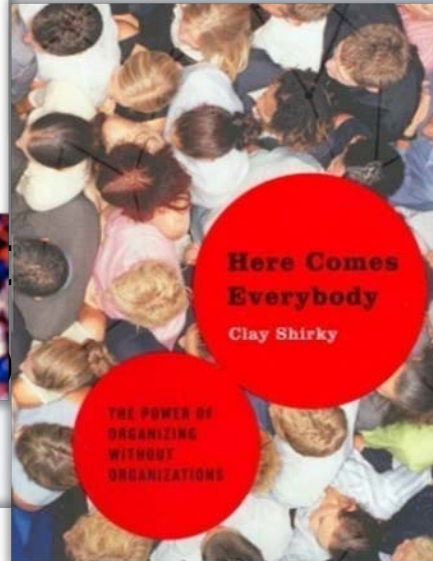
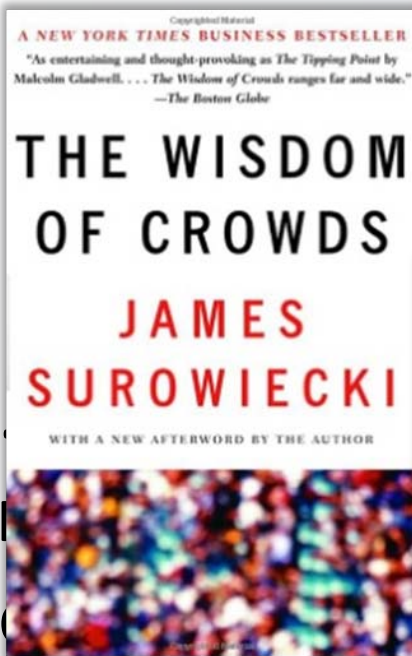
Average Customer Review

★★★★★ (49 customer reviews)

Share your thoughts with other customers

Create your own review

The Science of Crowdsourcing



**COGNITIVE
SURPLUS**
CREATIVITY AND GENEROSITY
IN A CONNECTED AGE

**CLAY
SHIRKY**

Conditions Necessary
In certain circumstances, groups are
often smarter than
individuals.

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

Crowdsourcing Science - Researchers

GRID ENABLED MEASURES



Information Exposure
(e.g., Health Information National Trends Survey, HINTS)



Toxicant Exposures
(e.g., Breast Cancer & Environment)



Health Care Environment
(e.g., Cancer Research Network)



PopSci Grid (caBIG®)



Disease Registry Data (e.g., ePath)



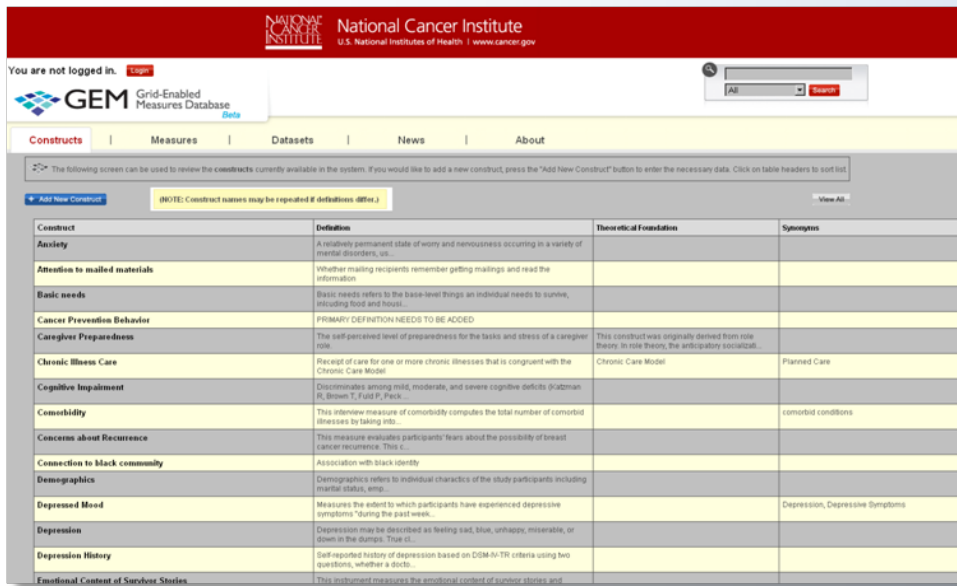
Benefits

- Cost effective
- Coordinated
- Transparent

Tensions

- No common vocabulary
- Individual vs. team incentives

Grid Enabled Measures (GEM): Science 2.0



You are not logged in. [Login](#)

GEM Grid-Enabled Measures Database

[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	Theoretical Foundation	Synonyms
Anxiety	A relatively 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 ADDED		
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 socialization...	
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	Discontinues among mild, moderate, and severe cognitive deficits (Jubman R, Brown T, Fuld P, Peck, ...)		
Comorbidity	This interview measure of comorbidity computes the total number of comorbid illnesses by taking into...		comorbid conditions
Concern 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, emp...		
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 or...		
Depression History	Self-reported history of depression based on DSM-IV-TR criteria using two questions, whether a disor...		
Emotional Content of Survivor Stories	This instrument measures the emotional content of a survivor 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:

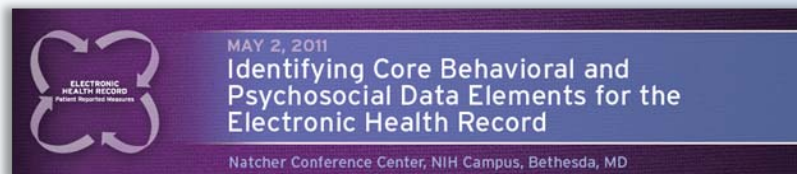
- vet and promote the use of shared measures— based on theoretically-meaningful constructs;
- share the resulting harmonized data.

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

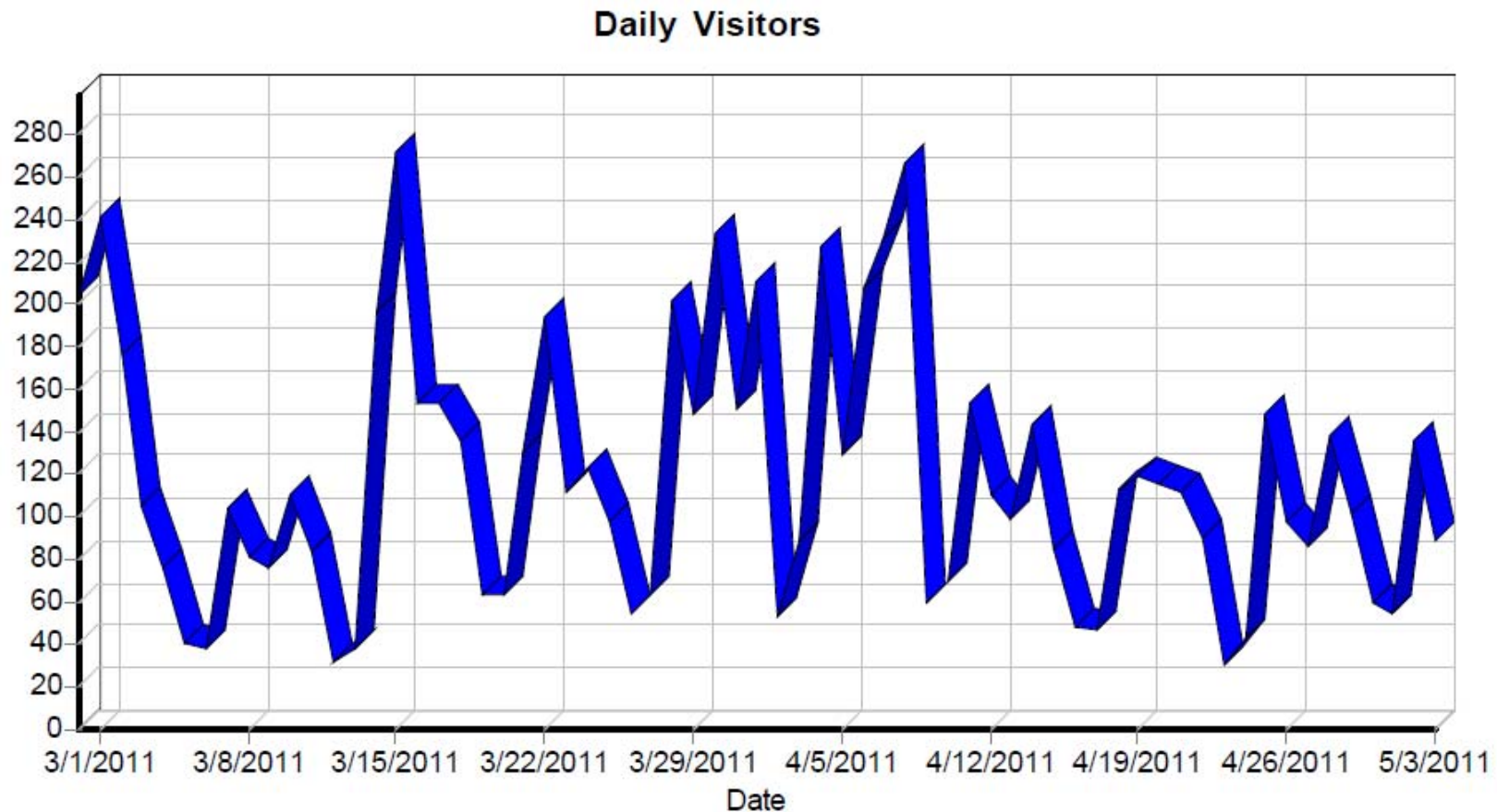
Electronic Health Records (EHR) Campaign



- December, 2010 to May, 2011
- Goal: To develop consensus on common data elements for patient-reported health behaviors and psychosocial factors for EHRs
- Assessed 13 constructs
- Consensus meeting held at NIH May 2-3, 2011




Participation in EHR Campaign



■ Totals:


- 1,000+ registered
- 296 comments (from 98 individuals)
- 603 ratings (from 60 individuals)

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)

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

HINTS GEM 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 HINTS Iterations (n=526)	Measures Newly Proposed 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%

GEM: Lessons Learned



- Small number of transgressions
- Most (public) work done by relatively few
- Infusion of new ideas
- Need to address barriers to participation



Crowd-Sourcing Science: Mass Participation in Knowledge Generation from the Public



Tools to track,
manage and
research asthma

Our GPS inhaler and mobile phone applications can help you learn more about your asthma and improve public health.

[Learn More](#)

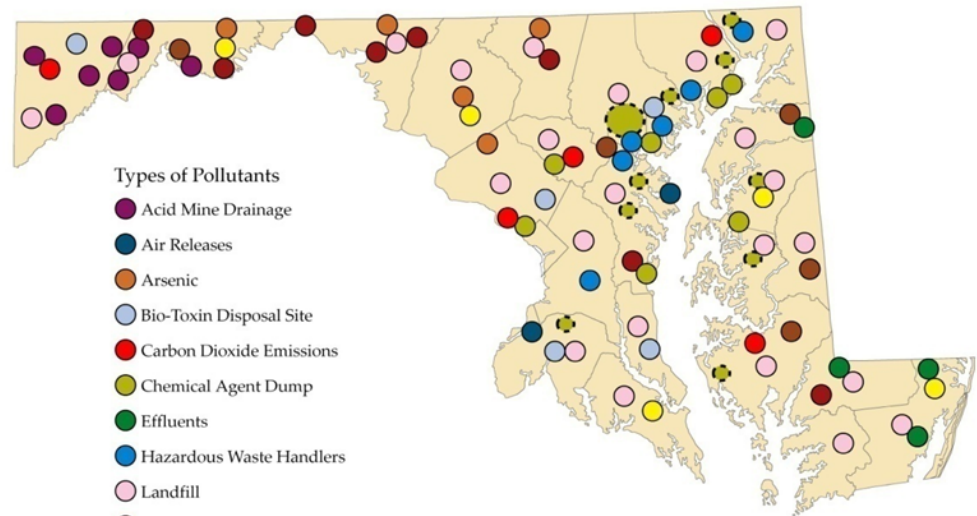
uses Asthmapolis?



Experts recommend that people with asthma track their symptoms, triggers and use of asthma

[About](#) [How It Works](#) [Blog](#) [Press](#) [Contact](#) [Careers](#)

Maryland Pollution



map produced by Nick Arnold, 2009
source: Environmental Protection Agency

Crowdsourcing Science - Public



331,000 women recruited since mid 2009;
Goal is 1,000,000 women

Benefits

- Reinvigorate public interest in science
- Overcome stumbling blocks to discovery (e.g., recruitment)
- Improve “n” / power

Tensions

- Need to update sampling statistics
- Coordination needed between advocacy groups and science
- Quality Control

"Citizen Science": Patients Offering Personal Data in a Disease-Oriented Commons

Benefits

- Improves likelihood of detecting side effects
- Permits social comparison
- May facilitate self-regulation processes

Tensions

- Need to renegotiate boundaries between private sector, public sector, and citizens
- New rules needed for rigor & control

The screenshot shows the homepage of 'patientslikeme'. At the top, there's a navigation bar with links for Patients, Treatments, Symptoms, and Research, along with a search bar. A login section is on the right with fields for Username or Email and Password, and buttons for Login, Remember me, Forgot password?, and Secure login. The main content area features a large blue banner with the text 'Find Patients Just Like You' and a sub-header 'Do you have a life-changing condition? Learn from the real-world experiences of other patients like you.' Below this is a 'Join Now! (It's free!)' button. To the right of the banner is a grid of patient photos and a quote: 'I don't think all the money in the world could replace what I've learned here.' —Multiple Sclerosis Community Member. Below the banner is a section titled 'CURRENT DISEASE COMMUNITIES' with a list of prevalent diseases: ALS/MND, Epilepsy, Fibromyalgia, Chronic Fatigue Syndrome/ME, HIV/AIDS, Mood Conditions, Anxiety, and Bipolar. To the right of this list are three icons representing different ways to interact: 'Share your health data', 'Find patients like you', and 'Learn from others'.

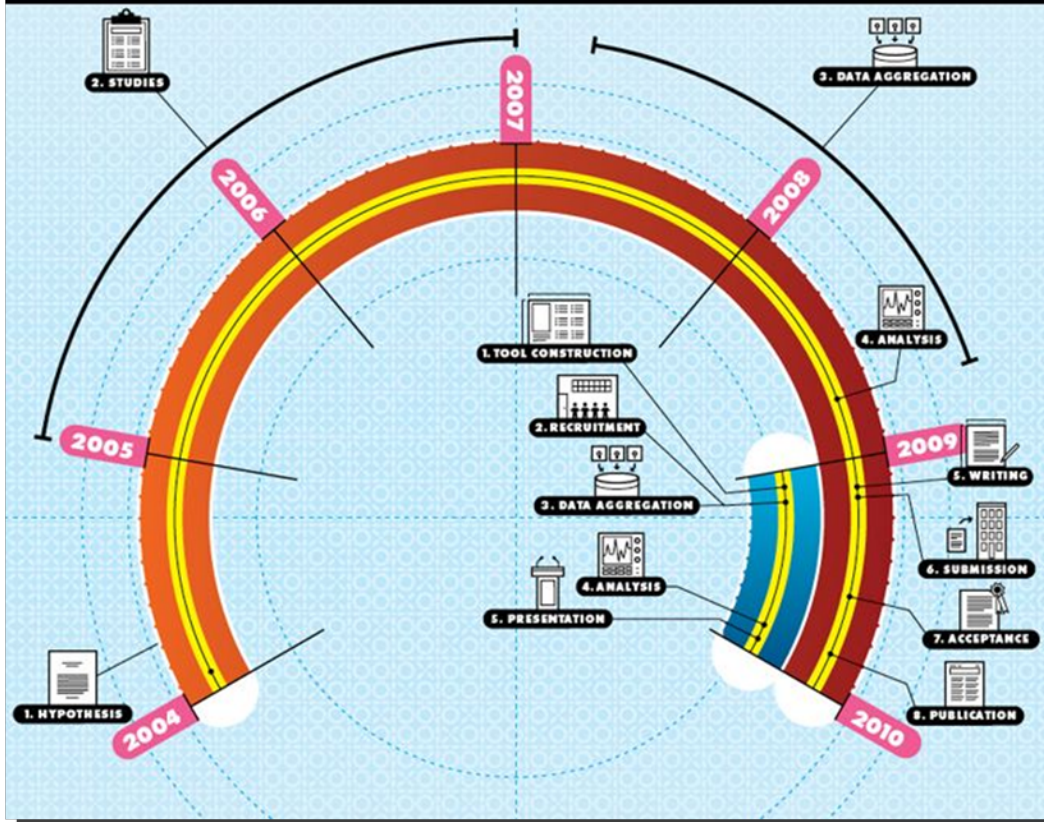


Traditional vs. “New” Science

WIRED

High-Speed Science

Can a model fueled by data sets and computational power compete with the gold standard of research? Maybe: Here are two timelines—one from an esteemed traditional research project run by the NIH, the other from the 23andMe Parkinson's Genetics Initiative. They reached almost the same conclusion about a possible association between Gaucher's disease and Parkinson's disease, but the 23andMe project took a fraction of the time.—*Rachel Swaby*



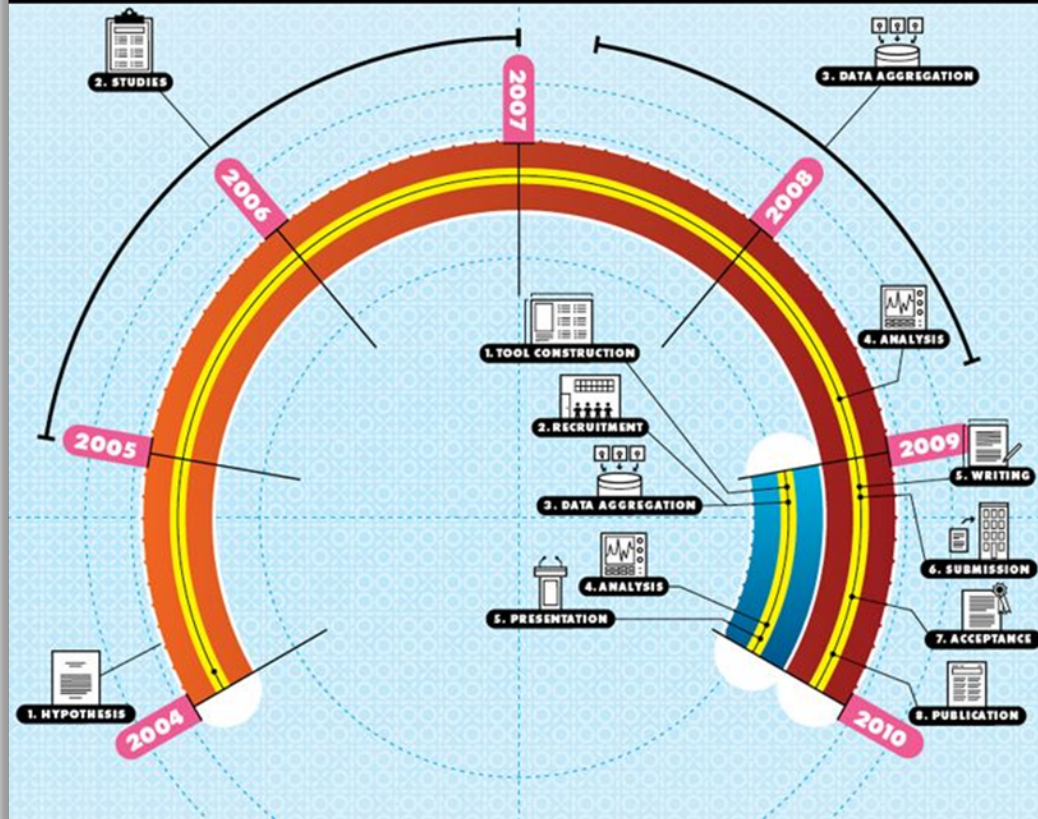
Traditional Model

- Hypothesis
- Studies
- Data aggregation
- Analysis
- Writing
- Submission
- Acceptance (NEJM)
- Publication

Time Elapsed: 6 years

High-Speed Science

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Genetics Initiative

- Tool construction
- Recruitment
- Analysis
- Presentation

Time Elapsed: 8 months



What's Next?

Is Science at the Table?

Science?



Is Science at the Table?: Proceed (with Caution)



- Emphasizing technology over science
- Finding the next 'killer app'
- No one size fits all
- Sampling issues/generalizability
- Need evidence-based applications

Nov, O., Arazy, O., and Anderson, D. (2011). Technology-Mediated Citizen Science Participation: A Motivational Model. *Proceedings of the AAAI International Conference on Weblogs and Social Media (ICWSM 2011)*. Barcelona, Spain, July 2011.

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Realizing the Promise of Web 2.0: Engaging Community Intelligence

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Discussions of Health 2.0, a term first coined in 2005, were guided by three main tenets: (a) health was to involve more participation, because an evolution in the

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Crowdsourcing: What does the Future Hold?

Wednesday, June 24, 2009

Big Brother crowd-sourcing

From NYT's [The Lede](#):

Update | 5:31 p.m. A reader, Jon, who has been in touch with via Skype, told him that a specific Web site of the Iranian government to identify protesters has been unable to get the site to load, possibly because it is under attack from supporters of the protesters. The information passed on by the reader was then asked to study photographs of protesters and then turn them in to the authorities.

Later: A reader points out that Google is running at least one page of photographs of faces of 25 protesters circled, and another page of people.

