



# CROWDSOURCING AND MEDICINE

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# OBJECTIVES





# WHAT IS CROWDSOURCING?

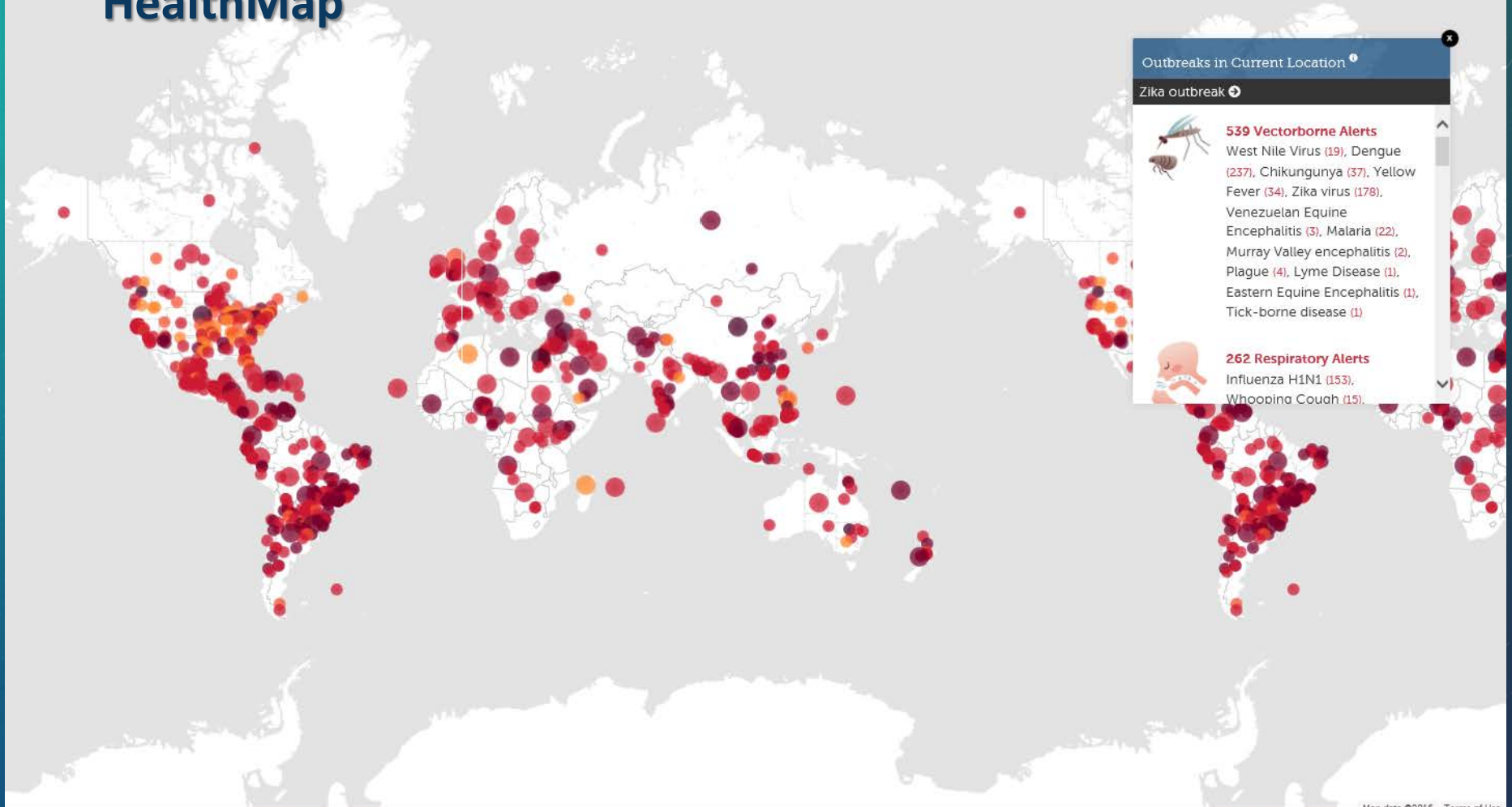
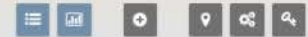
- Term coined in 2006 by Wired Magazine editors
- The process of obtaining needed services, ideas, or content by soliciting contributions from a large group of people, especially an online community, rather than from employees or suppliers
- Crowdsourcing combines the efforts of numerous self-selected volunteers or part-time workers; each person's contribution combines with those of others to achieve a cumulative result

# TOP 5 MEDICAL CROWDSOURCING SITES

- **HealthMap.org** - HealthMap.org monitors outbreaks such as Swine Flu and SARS around the world
- **SickWeather.com** - Sickweather.com searches your social networks for indicators of illness. It allows users to track conditions, compare symptoms and measure the proliferation of a virus in a specific region
- **Google Flu Trends** – no longer publishing data – was very useful
- **Global Public Health Intelligence Network (GPHIN)** - subscription-based service that monitors Internet media in nine languages in order to help detect and report potential disease outbreaks or other health threats around the world (appears to no longer be active – archived in 2013)
- **CrowdMed.com** - believes that diagnosis should be a team effort and invites everyone —practitioners, patients and the public at large — to be an “MD” (medical detective). By harnessing “the wisdom of crowds” to help solve complicated medical cases



# HealthMap



**Outbreaks in Current Location**

Zika outbreak

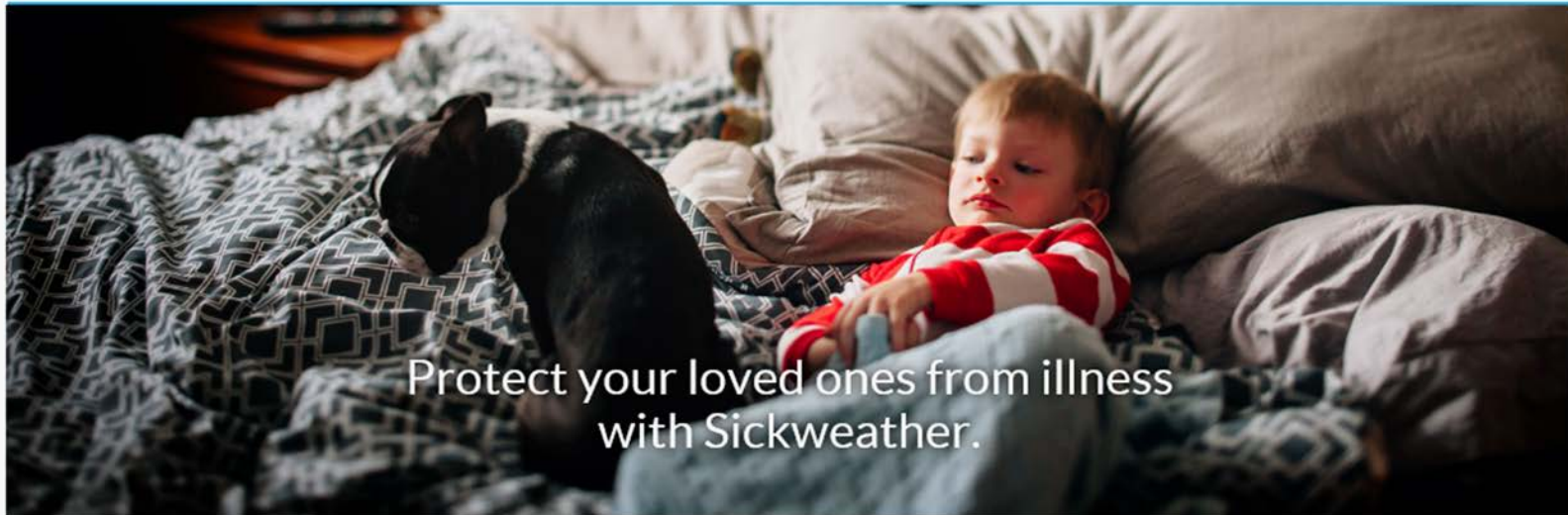
**539 Vectorborne Alerts**

- West Nile Virus (19), Dengue (237), Chikungunya (37), Yellow Fever (34), Zika virus (178), Venezuelan Equine Encephalitis (3), Malaria (22), Murray Valley encephalitis (2), Plague (4), Lyme Disease (1), Eastern Equine Encephalitis (1), Tick-borne disease (1)

**262 Respiratory Alerts**

- Influenza H1N1 (153), Whoopina Cough (15)

Map data ©2016 Terms of Use



Protect your loved ones from illness with Sickweather.



## Sickweather - Sickness Forecasting & Mapping

Everyday thousands of people around the globe update social media sites like Facebook and Twitter when they (or someone close to them) get sick. Just as Doppler radar scans the skies for indicators of bad weather, Sickweather scans social networks for indicators of illness, allowing you to check for the chance of sickness as easily as you can check for the chance of rain.

[See How Sickweather works](#)



- Stay in the know**  
 Get real-time sickness alerts when you enter a sick zone.
- Keep it social**  
 Share forecasts and reports with your friends & Sickweather Groups
- Live map**  
 Find recent illness reports nearby, or across the country.



## Sickweather Apple Watch App with SickScore®

Our new Apple Watch app has features to help keep you and your family



# CrowdMed

TEDMED

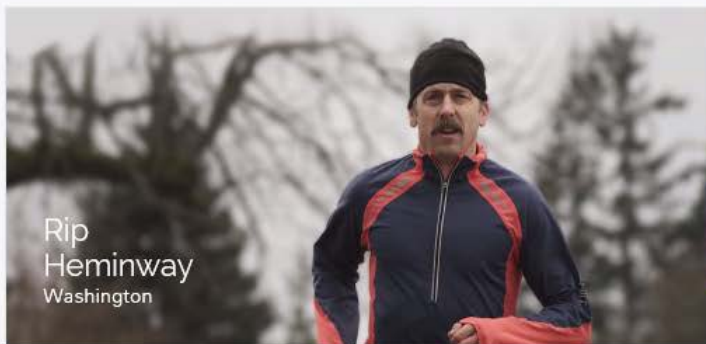
abc NEWS

WALL STREET JOURNAL

CBS

## We're Here to Help

We've solved the cases of patients from around the world. Our community of case solvers work together...



Rip Heminway  
Washington



Dianna Cleaveland  
New Hampshire

I can't thank the founders of CrowdMed enough. After years of struggling and living in terrified uncertainty, I actually have a diagnosis and am beginning treatment.

Patient "Walter"  
Washington, DC

CrowdMed has been the breath of fresh air for which I have been desperately searching for years. It may very well be the one thing that will give me back control of my life.

Patient "Tandra"  
Macon, Georgia

All of the 'detectives' who participated were extremely helpful, friendly and conscientious in seeking more info. CrowdMed went beyond what any MD or specialist has done for me, so far.

Patient "Lizette"  
Monkstown, Canada

# FOOD SOURCE INFORMATION WIKI

- Created in 2013 by Colorado School of Public Health and Colorado Department of Public Health and Environment
- Includes basic and timely information on food production practices and distribution systems
- Content written and reviewed by individuals and groups across the U.S.
- Aims are to bridge important knowledge gaps about foods suspected or implicated during foodborne illness outbreaks and improve outbreak response nationwide



# A food production wiki for public health professionals

Find help! Enter search term here.

Search



## About

This Wiki is an interactive website created as a working guide to food production methods for public health professionals.

Continue



## FSI Wiki Articles

Articles include pages about production methods for individual food items. Please visit the contact page to become an editor.

Continue



## Contribute to the Wiki

Contribute to the wiki! Author a new article, edit or add onto an existing article, or suggest a topic using our submission form.

Continue

## Featured articles:

# PATIENTSLIKEME

- Launched in 2004 as a Crowdsourcing capability to find a cure for ALS
- Has morphed into a data collection and sharing capability that would be considered the epitome of a learning healthcare system
- Now has 200,000 patients on it and tracks 1,800 diseases
- Includes such diseases as ALS, MS, Parkinson's, AIDS and mood disorders
- Has developed a number of tools to help patients quantify/objectify their symptoms
- Has become one of the best tools for helping patients and the health care system become partners in finding cures and palliative treatments





# Live better, together!™

Making healthcare better for everyone through sharing, support, and research

Join now

(it's free!)



## Learn from others

Compare treatments, symptoms and experiences with people like you and take control of your health



## Connect with people like you

Share your experience, give and get support to improve your life and the lives of others



## Track your health

Chart your health over time and contribute to research that can advance medicine for all

## Member Stories: Paul talks about thriving with bipolar



"Our brother Stephen was living with ALS and we thought, 'there has to be a better way.' There is. By sharing our experiences, we can all contribute new data that can accelerate research and help create better treatments. Our experiences can actually change medicine... for good."

**Jamie & Ben Heywood**  
Co-founders, PatientsLikeMe

## News

[Digital Health Authority Monique Levy Joins PatientsLikeMe](#)

Monique will use her extensive experience to shape how PatientsLikeMe's life science partners leverage patient-centered strategies and technologies to transform their operations and meet emerging patient needs.

[Joy Morel Joins PatientsLikeMe](#)

As Senior Vice President, Marketing, Patient Engagement and Business Intelligence, Joy will lead the team that focuses on attracting and engaging new members and business partners.

[See all](#)

# CROWDMED

- Founded in 2012 and based on San Francisco
- Through Crowdsourcing, aims to identify illnesses that have gone without a diagnosis
- Has handled more than 400 cases since its launch in 2013 at TEDMED
- Most useful for patients with rare, unsolved conditions
  - Sick for eight years
  - Seen eight different doctors
  - Spent \$60,000+ in medical expenses
- 70% of patients using CrowdMed say it has helped them get closer to correct diagnosis or cure



# THE GOOD AND THE BAD

- CrowdMed has helped a number of patients; however,
- Bioethicists are concerned about the lack of privacy on the site as well as accuracy of diagnoses
- Regulatory experts feel CrowdMed is the “unauthorized practice of medicine”
- Some viewers feel that medical information has no place in Crowdsourcing
  - Feel that the site gives too much freedom to people suggesting all sorts of treatment suggestions that desperate patients may try and have harmful outcomes as a result
- The premise is to talk with various physician experts in the field to find a diagnosis and cure...but that does not always happen

- Recommended
- Highest Cash Compensation
- Highest Point Reward
- Highest Quality
- Most Difficult
- Most Recent
- Ending Soonest
- Random

Unresolved Medical Cases

Search Medical Cases



#7518

Advanced Osteoporosis

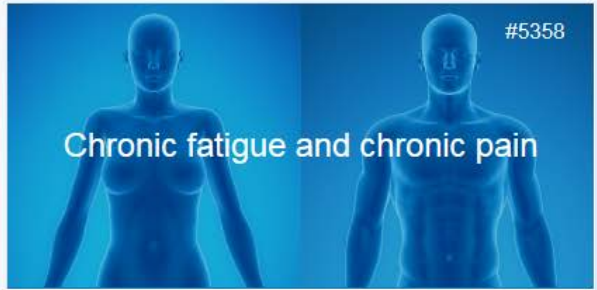
26 14,000 0 280

Tom

59 year old male · California, United States
After two and a half years of chronic back pain, during which I tried a number of therapies and treatments, I finally went to see an orthopedic doctor. He took ...

★★★★★

Follow Share View



#5358

Chronic fatigue and chronic pain

5 21,000 150 79

Cassey

54 year old female · Washington, United States
Daily chronic fatigue is my primary symptom. I often wake up tired and remain so for most of the day. Even when I sleep I usually have no more that 2-4 hours pe...

★★★★★

Follow Share View



#2193

Multiple complaints

14 15,000 100 82



#6300

Debilitating fatigue palpitations breathlessness pain

16 17,000 100 190



# BENEFITS OF CROWDSOURCING IN MEDICINE

- Benefit from the “Wisdom of the Crowd” in finding diagnoses and treatments for difficult to diagnose diseases and syndromes
  - This can be especially true if the “crowd” includes physicians across the country or globe with significant expertise
- With a large online community, such as PatientsLikeMe, can aggregate data on patients with uncommon diseases to help with both treatment research and improved diagnostic tools
- Can get peer or medical professional psychosocial support for dealing with a difficult illness/disease

# PROBLEMS/CONCERNS

- Patient privacy
- Accuracy of the diagnoses from the “crowd”
- Benefit/harm ratio of treatments from the “crowd”
- Cost/benefit ratio of the subscription service for paid crowdsourcing sites
- Participation of non-medical “crowd” members who may give advice that ultimately is harmful or misleading



# CONCLUSIONS

- Crowdsourcing as a concept has good literature support in the non-medical fields...Wikipedia, Kickstarter, LEGO Ideas, etc
- Crowdsourcing in medicine has an excellent example, PatientsLikeMe, but it has moved well beyond just a crowdsourcing capability
- CrowdMed has yet to prove its worth beyond a few hundred patients, with a number of questions/concerns about its function
- The Food Source Information Wiki appears to be a solid and rapid source for foodborne illness information
- Overall, we are still in the infancy of crowdsourcing in medicine...and it may not ever pan out beyond public health applications

# QUESTIONS AND COMMENTS

