Data Science for Drug Discovery, Health & Translational Medicine

Joanne S. Luciano https://www.linkedin.com/in/joanneluciano

Visiting Associate Professor
Indiana University School of Informatics and Computing

Question 3: How can data science help us all lead healthier lives?

Topics:

- Crowdsourcing

- Online communities

- ePatients

- Patient advocates

Learning Objectives:

The student will learn how the Web enables the wisdom of the crowd, i.e. how the web is being used to enable individuals to come together and help themselves and each other.

Crowdsourcing

The practice of obtaining information or input into a task or project by enlisting the services of a large number of people, either paid or unpaid, typically via the Internet. Main components:

- Identified tasks
- An online or open call for work
- A large group of globally distributed people, aka "the crowd"

Examples of how data are used or collected via crowdsourcing:

- Information management: [Crowds Care for Cancer](#) a 'survivors challenge' in conjunction with the National Cancer Institute (NCI)
- Medical research: Annotation in PUBMED abstracts
- Crowdsourcing Medical Decisions: Putting Big Data to Work in Healthcare
- Data collection: Several medical institutions around the world are using **ResearchKit** apps for collecting health data to study asthma, Parkinson's disease, diabetes, breast cancer, and cardiovascular disease.

http://health.oliverwyman.com/drive-innovation/2016/04/field_report_future.html

3

CureTogether - crowdsourcing
– Why it was started

Faren Inglett shares why CureTogether was started, talks about the larger purpose of what they are doing to help people who are suffering, and explains how you can help and how you can benefit.

http://curetogether.com/blog/2008/09/13/22/

CureTogether
– crowdsourcing personal experience

CureTogether

depression 🔍

Browse conditions

Your Health
Personal information
Condition scores

Connect
Members like you
Inbox
Invite

Settings
Sign out
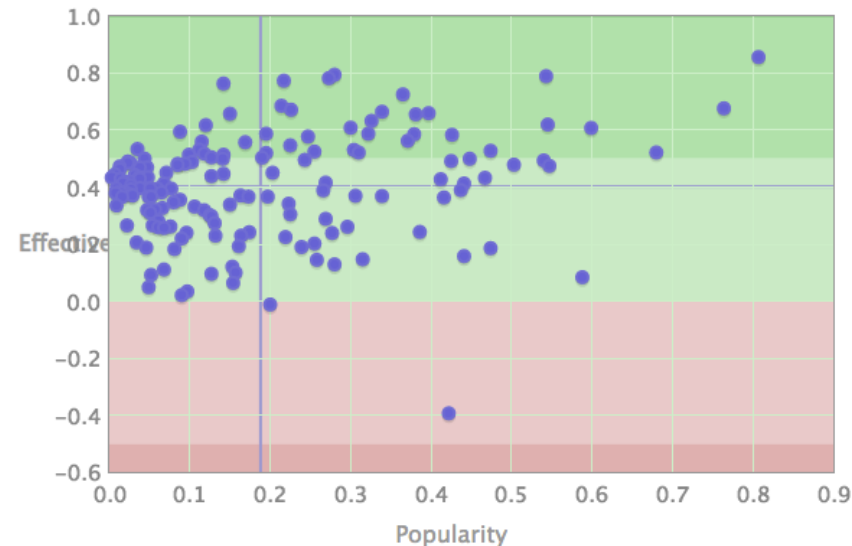
CureTogether is now part of 🧬 23andMe

learn more about your genetics

Depression (14,950 members)

Stats | Survey | Discuss | Infographic

160 Depression Treatments Compared
Hover over each dot to see what treatment it represents.

Effective Size (y-axis) vs Popularity (x-axis)

This infographic is based on a total of 35,964 treatment effectiveness ratings.

Read the blog post for this infographic or Take the survey yourself

Notes

x–axis = fraction of respondents who tried a given treatment
y–axis = average rated effectiveness of a given treatment
vertical blue line = average fraction of respondents who tried each treatment
horizontal blue line = average rated effectivenss of all treatments

Treatments in the upper–left quadrant have below–average usage, but above–average effectiveness, so presumably more people should be trying these. Those in the lower–right quadrant have above–average usage but below–average effectiveness, so presumably fewer people should be using these.

http://curetogether.com/depression/ig/treatment-effectiveness-vs-popularity
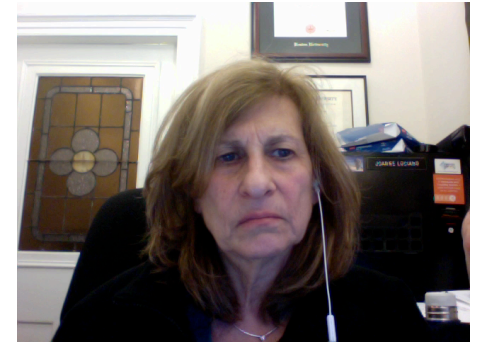
5

Online Communities

Online patient communities exist as:

- subgroups of social media sites
- non-profit organizations
- part of websites of healthcare organizations
- stand alone sites

Discussions provide information for both clinical and commercial purposes.

- education
- emotional support
- other resources
- information and tools for caregivers
- a forum for patients, caregivers, and providers to interact

David Lee Scher, MD Five Benefits of Online Patient Communities, Posted on June 20, 2013 https://davidleescher.com/2013/06/20/five-benefits-of-online-patient-communities/

ePatients

An e-patient is a health consumer

- participates fully in his/her medical care
- sees themself as equal partners with their doctors in the healthcare process
- gathers information about medical conditions that impact them
- uses the Internet and other digital tools

E-patients demonstrate the power of the Participatory Medicine

The "e" can stand for "electronic", "equipped", "enabled", "empowered" , "expert", engaged, etc.

https://epatient.care/

Patient Advocates

trained professionals who serves as a go-between for patients and their family members and representatives of the healthcare industry. Also known as health advocate, patient navigator, or care coordinator.

Patient Advocate services: https://advoconnection.com/advocacy-services/

- **DIY HEALTH**, **Patient Advocates Fight for Access to Medical Data: 'It's a Matter of Life and Death'** By **Christina Farr**MAY 11, 2015 https://ww2.kqed.org/futureofyou/2015/05/11/patient-advocates-fight-for-access-to-medical-data-its-a-matter-of-life-and-death/

- **Big Data for Patients (BD4P)** is a data science training program for patient advocates: http://www.reaganudall.org/our-work/bd4

Big Data for Patients (BD4P)

BD4P

Reagan-Udall Foundation
FOR THE FOOD AND DRUG ADMINISTRATION

https://c-path.org/about/   http://www.reaganudall.org/