Patient Identification

Identifying patients and their preferences and understanding the patient preference paradigm.

For the online webcast: *Please submit your questions to the panel via the chat box. The online hosts will be collecting the questions during the session to be brought to the panel moderator during the panel discussion.*

Moderator: ***Martin Ho, M.S.***
Mathematical Statistician
CDRH/Office of Surveillance and Biometrics

Panel: ***David Hickam, M.D., M.P.H.***
Patient Centered Outcomes Research Institute (PCORI)

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Hill-Rom Company, Inc.
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John Wilbanks
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PatientsLikeMe

CDRH Center for Devices and Radiological Health

Identifying Patients and their Preferences and Understanding the Patient Preference Paradigm

David H. Hickam, MD MPH
Director, Program on the Assessment of Prevention, Diagnosis and Treatment Options
Patient-Centered Outcomes Research Institute (PCORI)

Patient Preference Initiative Workshop
Silver Spring, MD
September 18, 2013

pcori

What is Patient Centered Outcomes Research?

Patient-Centered Outcomes Research (PCOR) helps people and their caregivers communicate and make informed health care decisions.

PCOR is a type of comparative effectiveness research.

PCOR has the following characteristics:

•Actively engages patients and key stakeholders throughout the research process.

•Compares important clinical management options.

•Evaluates the outcomes that are most important to patients.

- Problem of measurement once outcomes are prioritized.

•Addresses implementation of the research findings in clinical care environments.

What Roles should Patients and Stakeholders Play in Research Teams?

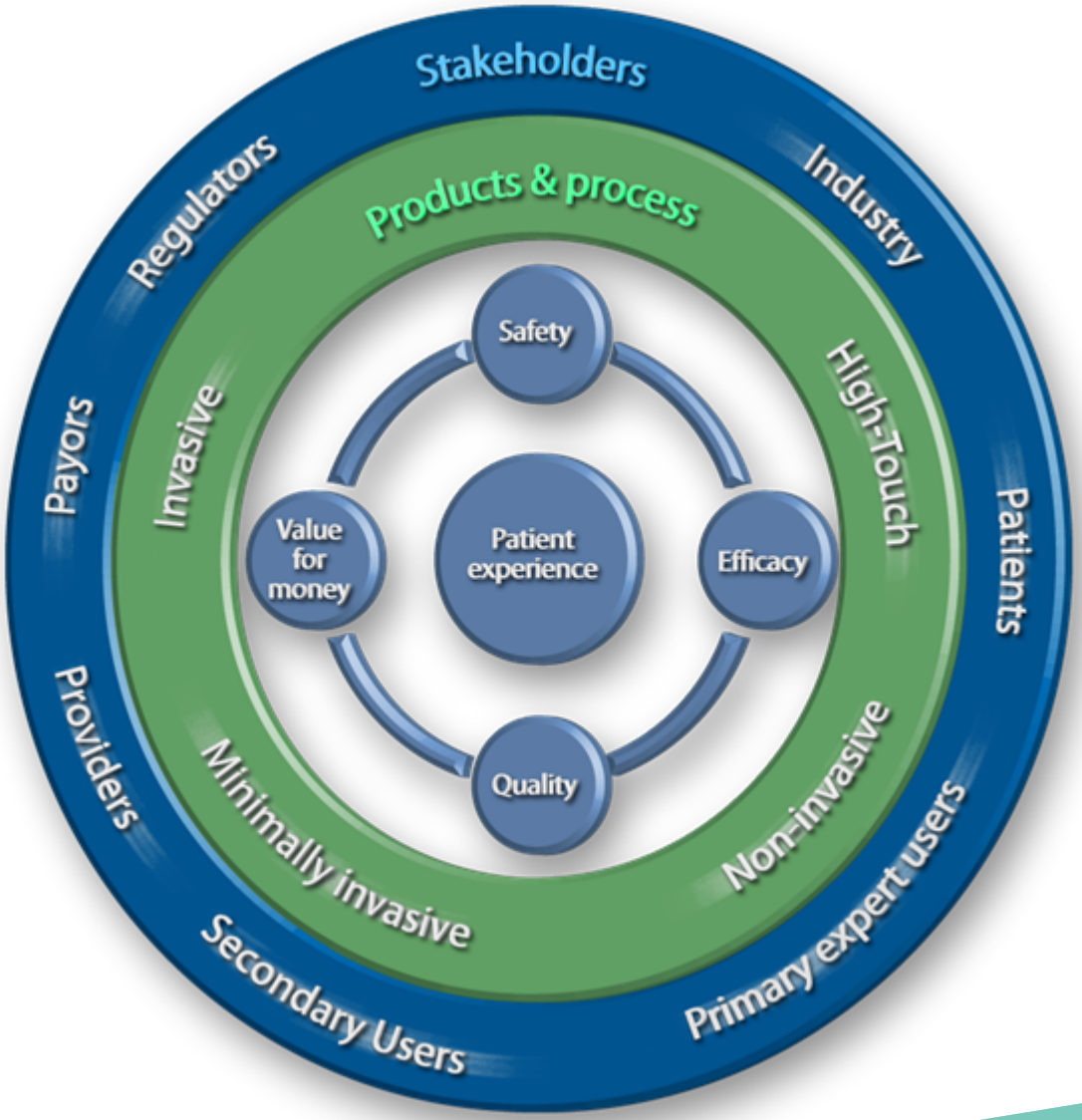
The engagement of patients and stakeholders should include:

- Participation in formulation of research questions;
- Defining essential characteristics of study participants, comparators, and outcomes;
- Monitoring of study conduct and progress; and
- Dissemination of research results.

Source: PCORI PFA Application Guidelines (Sec. 3.1.3.4) http://www.pcori.org/assets/PFAguidelines.pdf

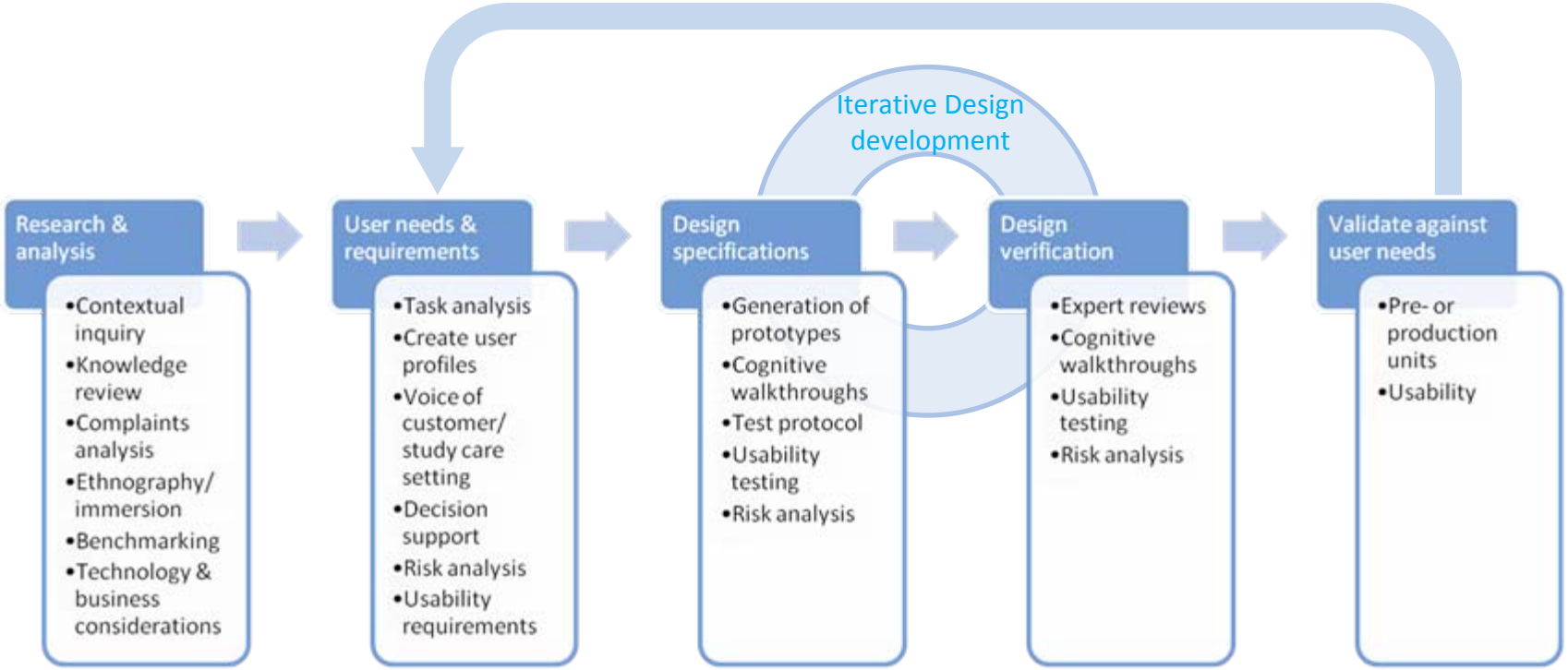
The patient – device – care delivery ecosystem

- Patient-centric principle that medical devices focus/deliver on: Safety, efficacy, quality, value
- A spectrum of medical devices addressing a variety of diseases, clinical processes & settings address needs of different users
- Patients, expert users and/or stakeholders can comprise the user profile and govern product design requirements
- Other factors in product development: Core competencies, intellectual property, technology, economics, strategic fit within company.



Usability and product development:

How the preferences of the patient and other users of a product are considered in medical device product development



John Wilbanks

Senior Fellow

Faster Cures

SOCIAL MEDIA, UNSTRUCTURED DATA AND IT'S APPLICATION IN MONITORING "VOICE OF THE PATIENT"

Mark Wolff, Ph.D.
Principal Industry Consultant
Health and Life Sciences Global Practice
SAS Institute

SHERLOCK HOLMES | PATIENT IDENTIFICATION

"…while the individual man is an insoluble puzzle, in the aggregate he becomes a mathematical certainty."

The Sign of the Four (1890) Sir Arthur Conan Doyle
Reference to *The Martyrdom of Man* (1872) William Reed

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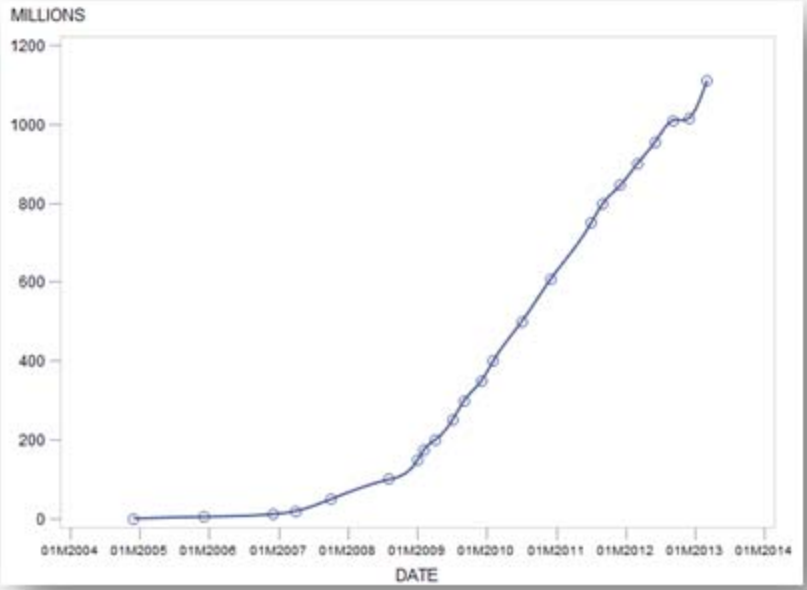
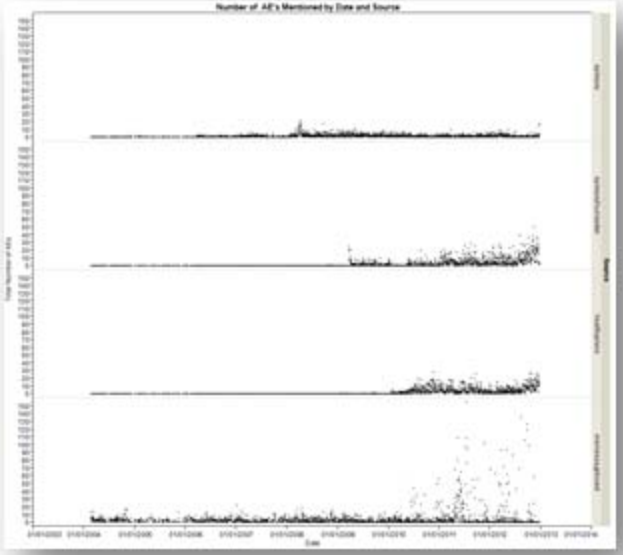
$Y=AB^X$ SOCIAL MEDIA AND SELF REPORTED DATA





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RECIPE | TEXT AND SEMANTIC TECHNOLOGY

- Collect
- Prepare
- Analyze
  - statistical modeling
  - natural language processing
  - Sentiment analysis
  - Advanced linguistic

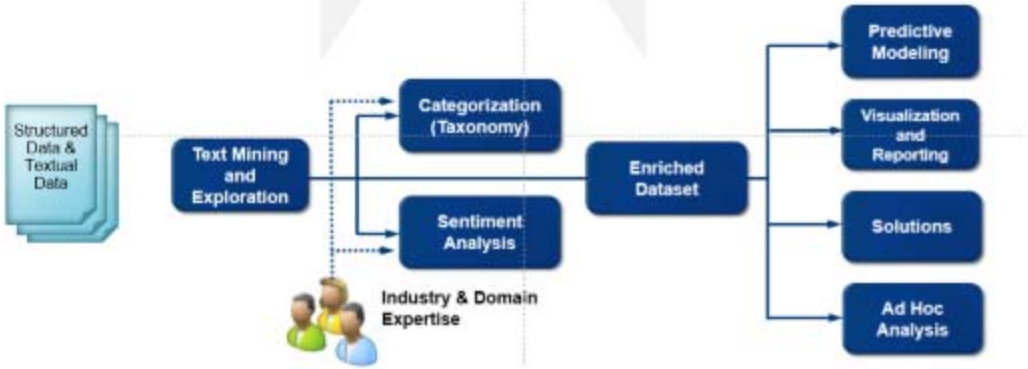
Identify meaning/patterns

Extract knowledge and insight

Model Behavior/Response

Temporal Network Analysis

Simulations



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VERACITY | THE PARADOX OF COMPUTER-MEDIATED COMMUNICATION

MARCH 4, 2013

Twitter Reaction to Events Often at Odds with Overall Public Opinion

By Amy Mitchell and Paul Hitlin

PewResearchCenter

Social media make us more honest

By **Jeffrey Hancock**, Special to CNN

updated 10:00 AM EST, Sun January 13, 2013

CNN

SOCIAL CONVENTIONS SEPTEMBER 2013

How to Catch a Liar on the Internet

Technology makes it easier than ever to play fast and loose with the truth—but easier than ever to get caught.

MEGAN GARBER | AUG 14 2013, 8:20 PM ET

The Atlantic

- Increasing use of social media derived data to support decision making
- Concerns related to accuracy and reliability

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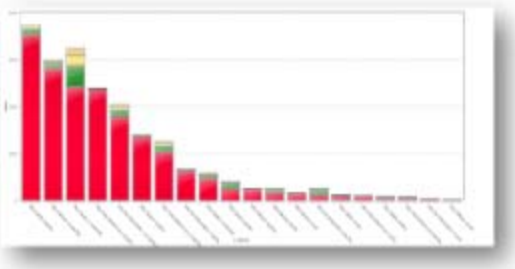
TRUST BUT VERIFY | UNSTRUCTURED DATA

Methods and Application for Determining the Integrity and Veracity of Medical Device Safety Related Data in Social Media

Social Media, Unstructured Data and it's Application in Monitoring "Voice of the Patient"



www.epilepsy.com

This directory is	: Negative
Number of articles	: 3113
Number of positive articles	: 938
Number of negative articles	: 1494
Number of neutral articles	: 431
Positive percent	: 30.13%

www.healthyplace.com

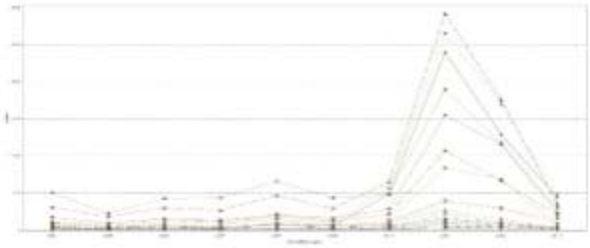
This directory is	: Negative
Number of articles	: 5114
Number of positive articles	: 1912
Number of negative articles	: 2526
Number of neutral articles	: 496
Positive percent	: 37.17%

www.epilepsyfoundation.com

This directory is	: Positive
Number of articles	: 6221
Number of positive articles	: 2369
Number of negative articles	: 2265
Number of neutral articles	: 992
Positive percent	: 38.08%

www.vmamessageboard.com

This directory is	: Negative
Number of articles	: 14066
Number of positive articles	: 2290
Number of negative articles	: 9694
Number of neutral articles	: 947
Positive percent	: 16.28%



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BIG IDEA | DYNAMIC SEARCH QUERY COHORT IDENTIFICATION

Imagine if you could…

…collect and process a corpus of data from countless, self reported, health related comments from the internet

...construct a “virtual patient” based on a set of specific criteria of interest

…explore the virtual patients attributes including their sentiment and preference in context of a specific disease state and medical device

…have a high level of confidence that the virtual results, represent a reality of interest

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patientslikeme®

Our approach:

Provide patients the tools and structure within which their data and experiences are collected, measured, aggregated and understood.

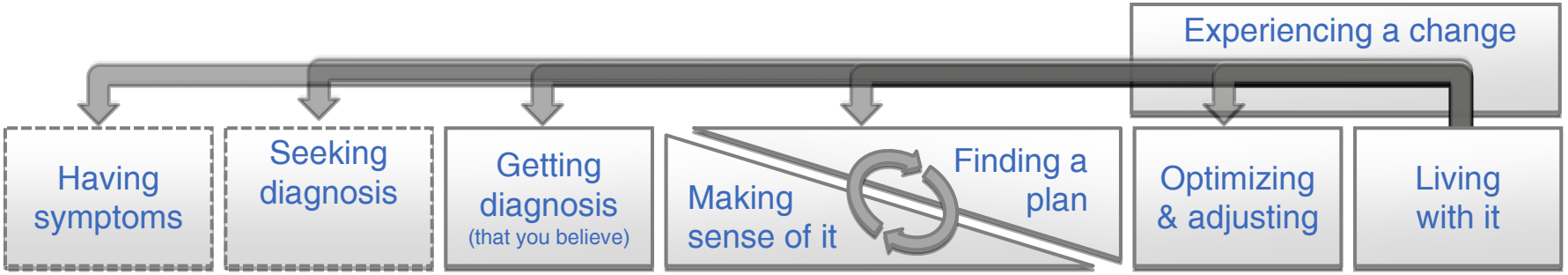
Patient Identification

Using persona based design…

- Who are the patients most likely to participate in an on-line patient-powered research network?
  - Tweaker / tracker
  - Interested in research
  - Advocate / leader
  - Social networks
- Inventory of existing measures and end points
- Input from clinical specialists and researchers
- Ethnographic interviewing in the field with patient members and non-members
- Understanding the condition across the trajectory

Condition development:

Understanding the journey…



patientslikeme®

What is **Parkinson's Disease**?

Parkinson's Disease is a progressive disorder of the nervous system marked by muscle tremors, muscle rigidity, decreased mobility, stooped posture, slow voluntary movements, and a mask-like facial expression.

Do you have Parkinson's? Join now to connect with patients like you!

What is it like to have Parkinson's?

Common symptoms	How bad it is	What people are taking for it
Deteriorating mental ability (dementia)		Memantine, Galantamine, Rivastigmine
Slowness		Carbidopa-Levodopa CR, Carbidopa-Levodopa, Pramipexole
Memory problems		Mental Exercise, Donepezil, Rivastigmine
Stiffness/Spasticity		Carbidopa-Levodopa, Ropinirole, Rasagiline
Pain		Hydrocodone-Acetaminophen, Ibuprofen, Gabapentin
Insomnia		Zolpidem, Clonazepam, Trazodone
Depressed mood		Citalopram, Escitalopram, Bupropion
Excessive daytime sleepiness (somnolence)		Vitamin C (ascorbic acid), Modafinil, Armodafinil
Excess saliva		Carbidopa-Levodopa, Gum Chewing, Nortriptyline
Fatigue		Modafinil, Amantadine, Methylphenidate
Constipation		Polyethylene Glycol 3350, Stool Softener, Fiber supplement
Anxious mood		Clonazepam, Alprazolam, Lorazepam
Sexual dysfunction		Carbidopa-Levodopa, Vardenafil, Tadalafil

Severe Moderate Mild None

Who has Parkinson's **at PatientsLikeMe?**

7,430 patients have this condition

125 New patients joined this month

7,274 say Parkinson's is their primary condition

Current Age

48% Females
52% Males

Gender

Age at first symptom

0-19 years	46
20-29 years	160
30-39 years	547
40-49 years	1,084
50-59 years	1,341
60-69 years	790
70+ years	219

Types

Drug-induced Parkinsonism	70
Inherited (genetic) Parkinson's disease	361
Parkinsonism (unknown cause)	1,168
Parkinson's disease	3,813
Vascular Parkinsonism	31

Diagnosis status

Not Diagnosed	161
Diagnosed	4,861

These charts show data from Parkinson's patients who have completed their condition history

What do patients take to treat Parkinson's and its symptoms?

Treatments reported by members	Perceived effectiveness	Overall rating of side effects	# of Evaluations
Carbidopa-Levodopa			390
Rasagiline			278
Ropinirole			270
Pramipexole			233
Amantadine			145
Carbidopa-Entacapone-Levodopa			123
CoQ10 (CoEnzyme Q10)			74
Carbidopa-Levodopa CR			54
Deep Brain Stimulation (DBS)			53
Selegiline			52
Entacapone			39
Rotigotine			37
Levodopa-Benserazide			22
Trihexyphenidyl			19
Physical Exercise			15

These charts show data from Parkinson's patients' latest treatment evaluations

patientslikeme®

Panel Questions

- How to identify patients and their preferences?
- Who is a representative patient? What is the average patient? How do you address patient heterogeneity?
- How can the spectrum of patients be represented?
- What type of information can/should patients provide?
- What types of information do patients use to formulate decisions about their treatment options?
- Where can patient preference information be found?

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Center for Device and Radiological Health