

Patient-Centered Research Dissemination: Practical Social Media Strategies

UMD CER-PCOR Summer Institute

August 10, 2016



Emil Chiauzzi, PhD

Research Director | PatientsLikeMe

The Research Journey: Key Components



Customization

- On Ofev or Esbriet
- Not on either treatment, but aware of them
- Not on either treatment, and not aware of them



Concierge

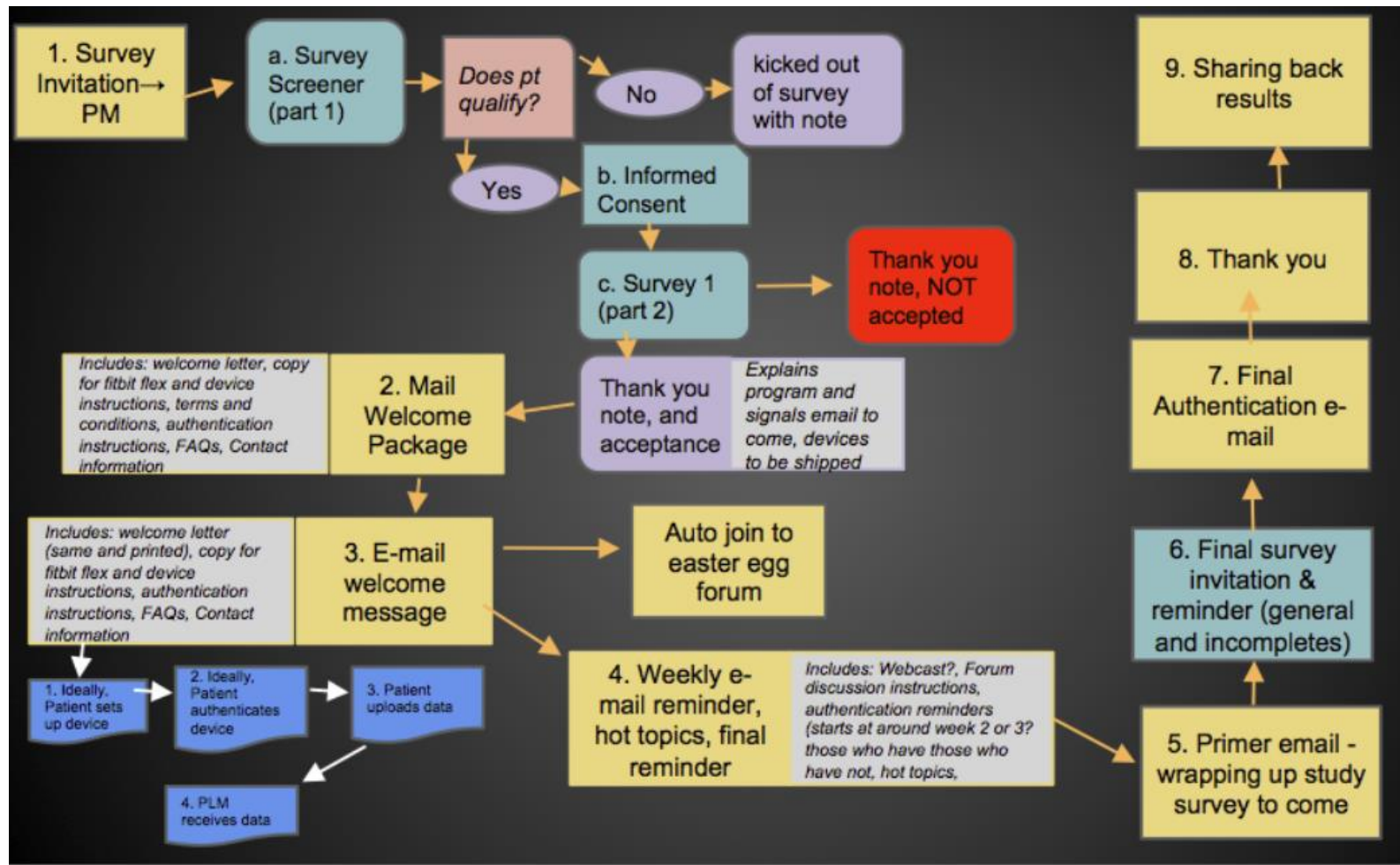
- “Hi, I’m Dave!”
- Give a face to the experience, make it human
- One point of contact



Give back

- Give data, get data philosophy
- Create cyclical engagement, not one time action
- Everyone learns, no one is left behind

Device Study Journey Map



Team of Advisors



Jill Biden Visit



Team of Advisors Best Practices Guide

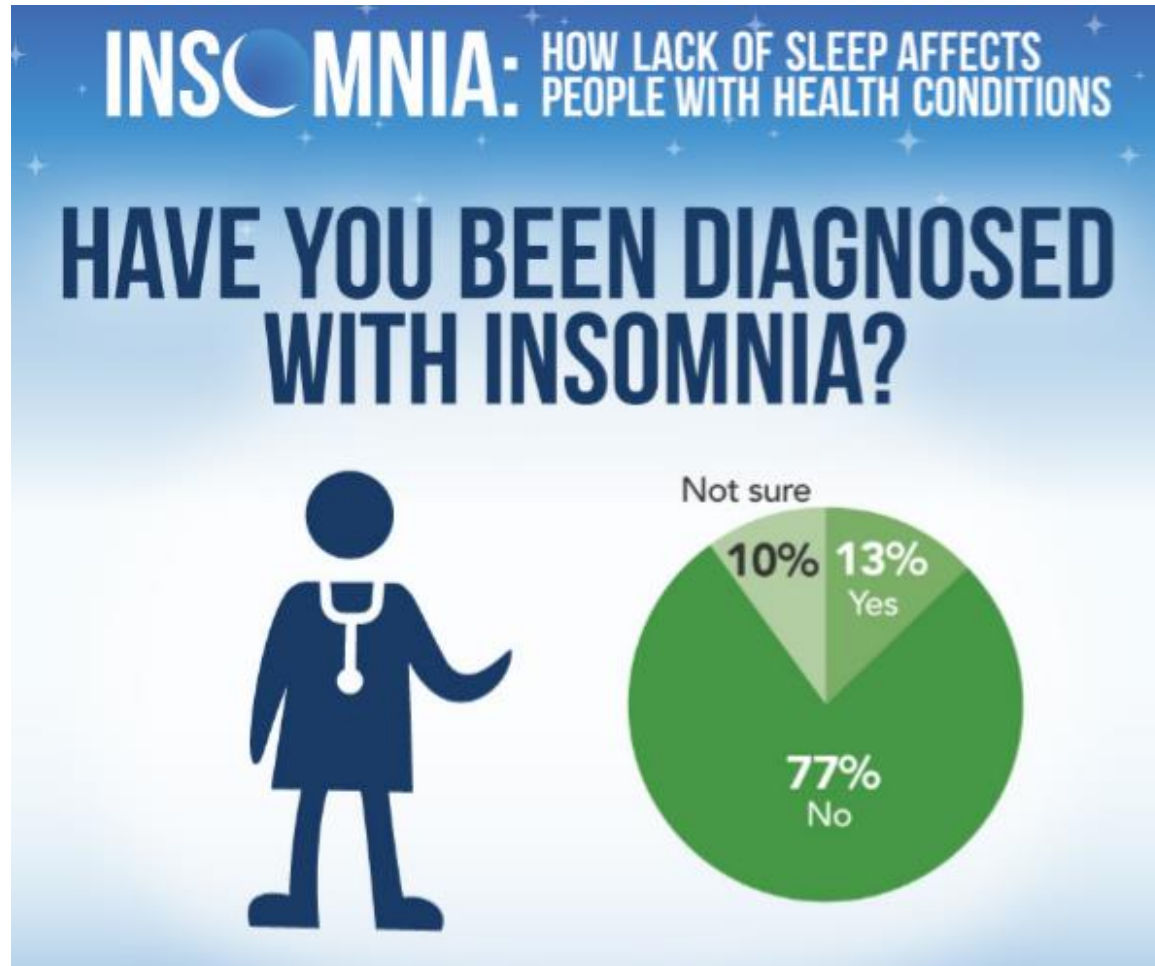
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BEST PRACTICES GUIDE FOR (ONLINE) RESEARCHERS

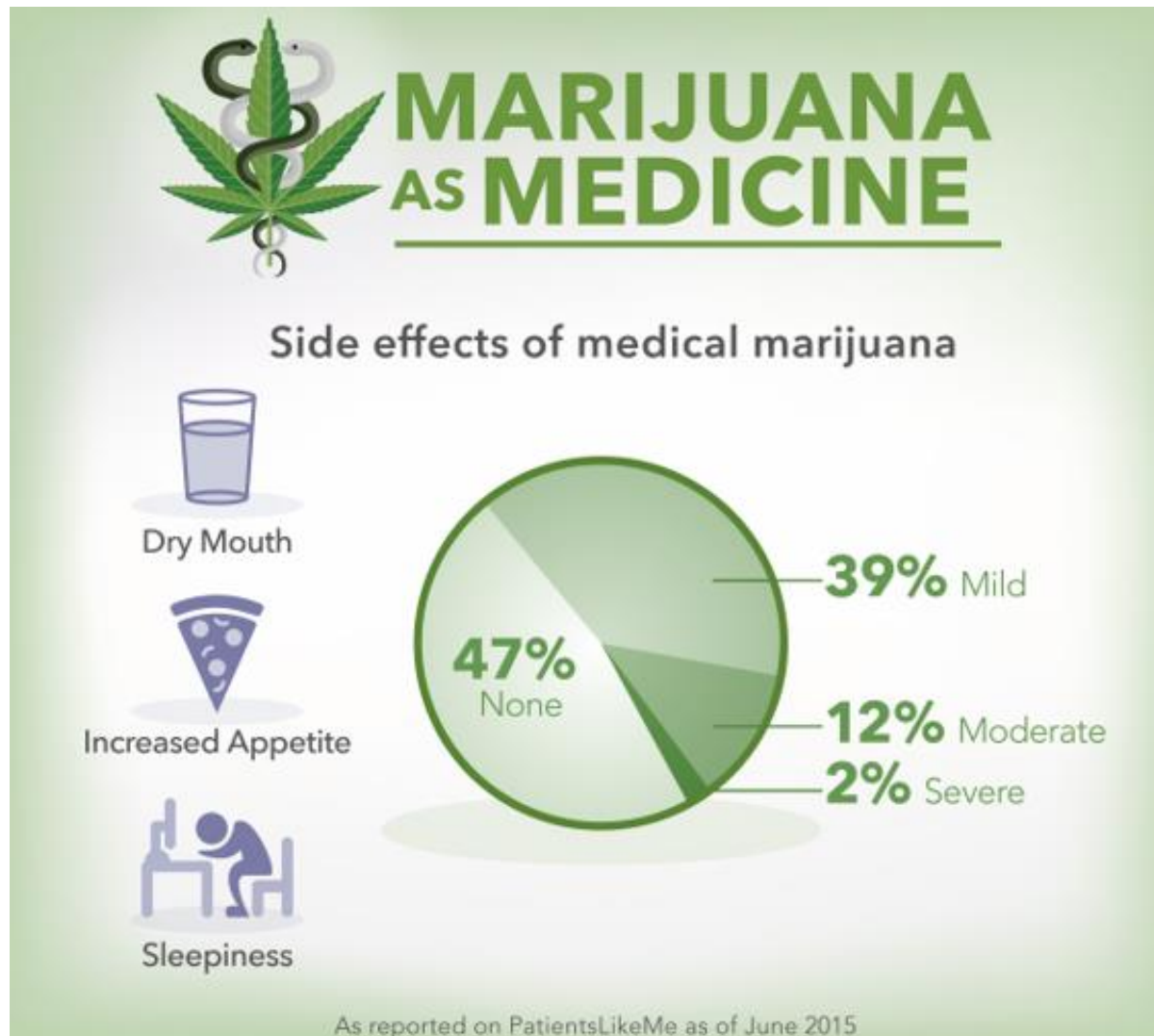
At PatientsLikeMe we believe patients should be at the center of healthcare – in how we learn about disease, in treatment and care decisions, and integrated throughout the research process. The growth of online communities (like PatientsLikeMe) has introduced new ways to partner with patients in meaningful ways. How, though, do researchers and the organizations that support research actually do this?

http://patientslikeme_mkting.s3.amazonaws.com/Best%20Practices%20Guide.pdf

Give Data, Get Data



Give Back



Event-Related Blogs

Migraine & Headache Awareness Month: New insights from a recent study

Posted June 16th, 2016 by [patientslikeme](#)



It's National Migraine and Headache Awareness Month, so let's help spread that awareness by sharing the results of a recent survey that 300 members from the migraine community on PatientsLikeMe took.

For this study, we defined chronic migraine as having had 15 or more headaches in the past month. Here's what members helped uncover:

High level takeaways:

Some of these high level results might seem obvious, but we first wanted to set a baseline for what the community was experiencing.

- The more they experience migraines, the more types of symptoms they report and the worse those symptoms are.
- Also the more they experience migraines, the worse their overall quality of life becomes for things like their ability to be active and their emotional experiences.
- Those who experience chronic migraines more often report also living with anxiety disorders.

Facebook



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PatientsLikeMe
4 hrs · 🌐

Are you living with #Crohns disease? How do your symptoms compare to those reported by PatientLikeMe members?
<http://bddy.me/2aT1bQu>

Common symptoms	How bad it is	What people are taking for it
Abdominal pain		Tramadol, Fentanyl Transdermal Patch, Gallbladder removal (cholecystectomy)
Blood in stool		Anti-Inflammatory Diet, Iron supplement, Prednisone
Fatigue		Modafinil, Vitamin B12 injection, Vitamin B Complex
Diarrhea		Loperamide, Diphenoxylate and Atropine, Rifaximin
Insomnia		Zolpidem, Trazodone, Amitriptyline
Pain		Tramadol, Hydrocodone-Acetaminophen, Pregabalin
Anxious mood		Clonazepam, Alprazolam, Lorazepam
Vomiting		Cannabis, Cyclizine
Mucus in stool		Mesalamine
Bowel urgency		Solifenacin, Colesevelam

Medical & Health · Cambridge, Massachusetts
4.5 ★★★★★

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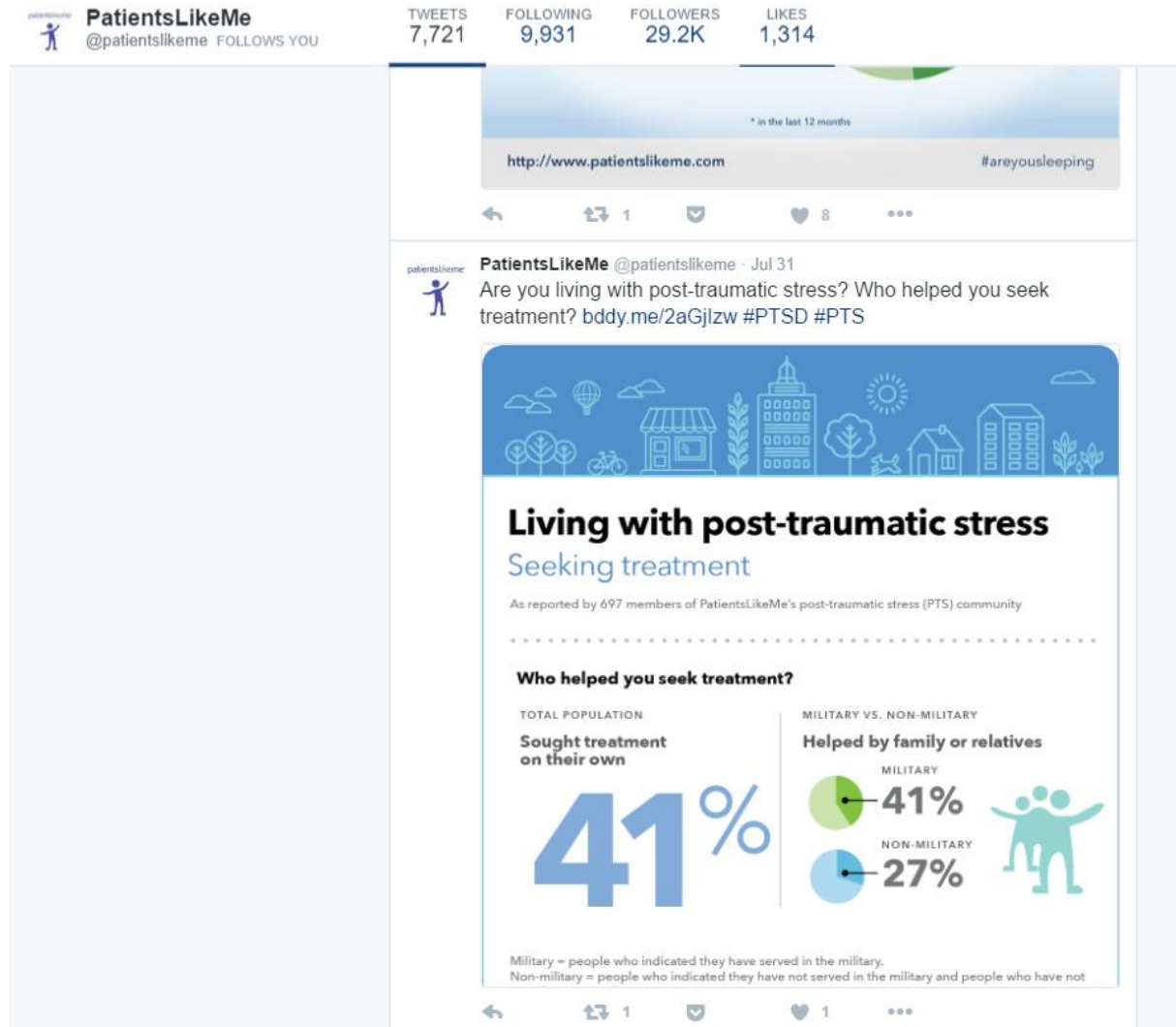
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The Patient - Patient-Centered Outcomes Research

..... pp 1-13

Factors in Patient Empowerment: A Survey of an Online Patient Research Network

Emil Chiauzzi , Pronabesh DasMahapatra, Elisenda Cochlin, Mikele Bunce, Raya Khoury, Purav Dave

Open Access | Original Research

Article

First Online: 07 May 2016

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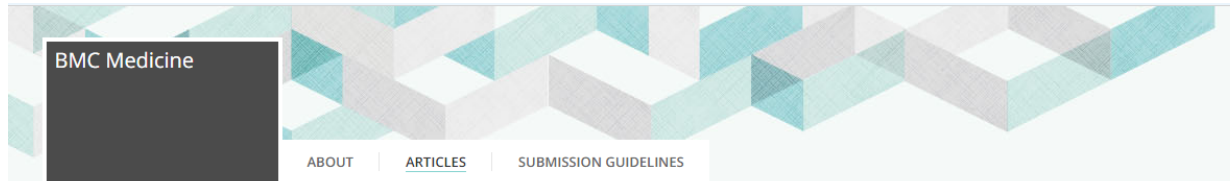
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PLM Publications



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OPINION | **OPEN ACCESS**

Patient-centered activity monitoring in the self-management of chronic health conditions

Emil Chiauuzi , Carlos Rodarte and Pronabesh DasMahapatra

BMC Medicine 2015 13:77 | DOI: 10.1186/s12916-015-0319-2 | © Chiauuzi et al.; licensee BioMed Central. 2015
Received: 23 November 2014 | Accepted: 10 March 2015 | Published: 9 April 2015

 Open Peer Review reports

Abstract

Background

As activity tracking devices become smaller, cheaper, and more consumer-accessible, they will be used more extensively across a wide variety of contexts. The expansion of activity tracking and personal data collection offers the potential for patient engagement in the management of chronic diseases. Consumer wearable devices for activity tracking have shown promise in post-surgery recovery in cardiac patients, pulmonary rehabilitation, and activity counseling in diabetic patients, among others. Unfortunately, the data generated by wearable devices is seldom integrated into programmatic self-management chronic disease regimens. In addition, there is lack of evidence supporting sustained use or effects on health outcomes, as studies have primarily focused on establishing the feasibility of monitoring activity and the association of measured activity with short-term benefits.

Discussion

Monitoring devices can make a direct and real-time impact on self-management, but the validity and

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Patient-centered activity monitoring in the self-management of chronic health conditions

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Authors Emil Chlauzzi, Carlos Rodarte, Pronabesh DasMahapatra

Abstract As activity tracking devices become smaller, cheaper, and more consumer-accessible, they will be... [\[show\]](#)

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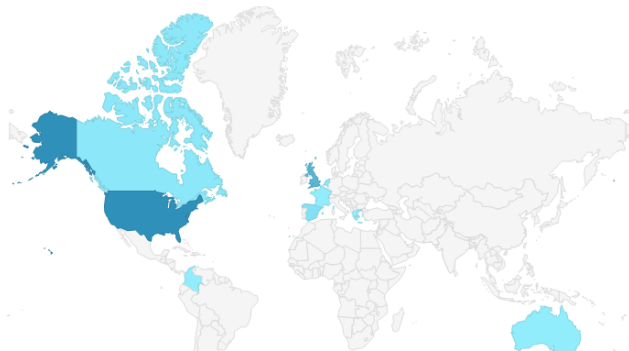
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ATTENTION SCORE IN CONTEXT

The data shown below were collected from the profiles of 133 tweeters who shared this research output. [Click here to find out more about how the information was compiled.](#)



Geographical breakdown

Country	Count	As %
United States	40	30%
United Kingdom	24	18%
Spain	7	5%
Canada	4	3%
Australia	2	2%
Netherlands	2	2%
France	2	2%
Colombia	2	2%
Greece	1	1%
Other	8	6%
Unknown	41	31%

<https://www.altmetric.com/details/3890414>

Patient Profiles in Publications

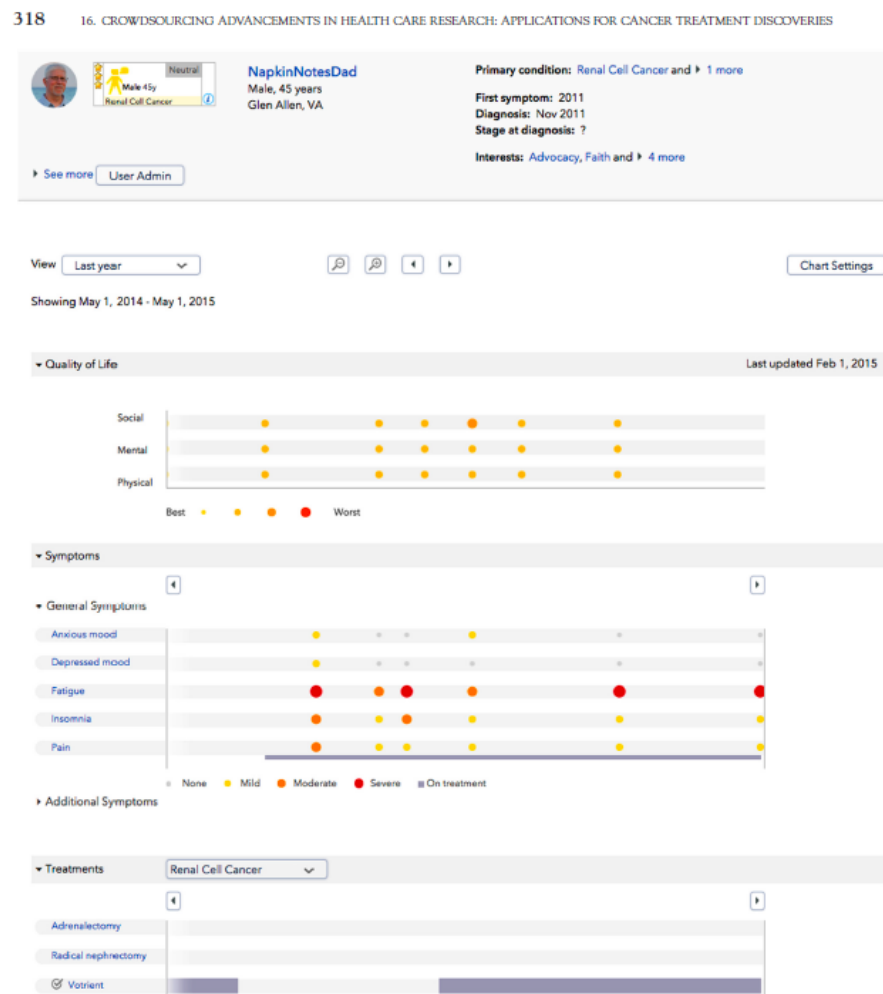


FIGURE 16.1 A profile of a PLM renal cell cancer patient.

Patients as Coauthors

VALUE IN HEALTH ■ (2016) ■■■■■



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Increasing Patient Involvement in Drug Development

Maria M. Lowe, PharmD, BCPS^{1,*}, David A. Blaser, PharmD¹, Lisa Cone, BA, Steve Arcona, PhD², John Ko, PharmD, MS², Rahul Sasane, PhD², Paul Wicks, PhD¹

¹PatientsLikeMe, Cambridge, MA, USA; ²Novartis Pharmaceuticals Corporation, East Hanover, NJ, USA

ABSTRACT

Background: To ensure the creation of treatments that maximize value at the lowest cost, all aspects of the health care system need to align with patient needs and preferences. Despite growing efforts to engage patients in research and regulatory activities, the pharmaceutical industry has yet to maximize patient involvement in the drug development process. **Objective:** To gain a better understanding of the present state of patient involvement in drug development. **Methods:** Through a semistructured interview methodology, we sought to identify opportunities, barriers, and examples of patient involvement in the drug development process. Telephone interviews were conducted with six senior leaders of evidence generation within the pharmaceutical industry and four patients. These interviews were supplemented with interviews with a research funder, a regulator, a patient advocacy group, and a caregiver. **Results:** Although our interviewees spoke of the potential benefits of aligning research around the needs of patients, there were few examples they could share to suggest this was occurring at scale. A number of barriers were identified including the added burden associated with adverse event

reporting, concerns about patient representativeness or their ability to participate in drug development conversations, and the costs in time and resources involved relative to returns on investment. **Conclusions:** As health care systems continue to evolve and establish patients as the primary stakeholder in their health care decision making, the pharmaceutical industry will need to be innovative to demonstrate the value of their products relative to the outcomes experienced by patients. Pharmaceutical companies should recognize the value of involving patients across the entire product life cycle and work to transform present perceptions and practices throughout their organizations.

Keywords: decision making, drug development, methodology, patient-centered.

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Tam Builds a New Health Measure



ALS Functional Rating Scale



One of our ALS patients, Cathy Wolf, expressed dissatisfaction in our forum that the ALSFRS-R (ALS Functional Rating Scale), the “gold standard” measure of ALS function, was insensitive at lower levels. Patients like her, or Stephen Hawking, could be rated a zero in terms of function, despite the fact they could still work, use the computer, and manage their affairs.

With her help as a co-investigator, we developed an extension that included three new items which conformed to the existing factor structure of the ALFRS-R. These relate to the ability to use fingers to manipulate devices, ability to show emotional expression in the face, and ability to get around inside the home.

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European Journal of Neurology: Measuring function in advanced ALS: Validation of the ALSFRS-R extension items

By Paul Wicks, Michael Massagli, Cathy Wolf, James Heywood

Publish Date:
Wednesday, May 20, 2009 3:00 am EDT

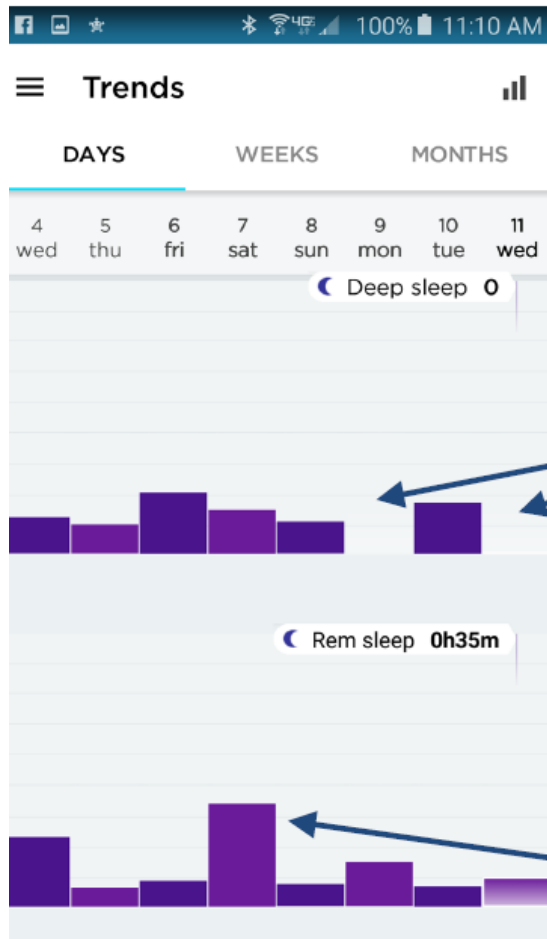
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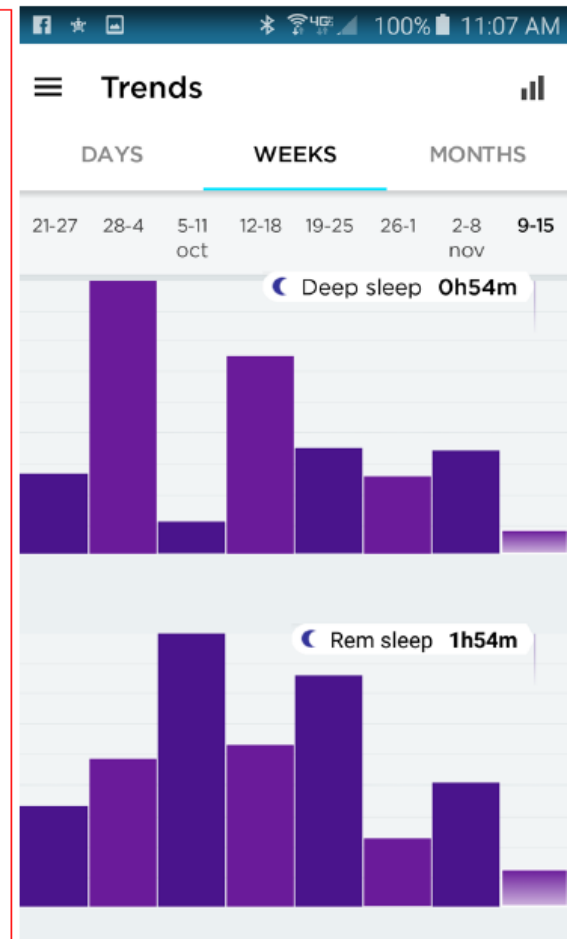
One of our ALS patients, Cathy Wolf, has had ALS for 10+ years and has been a psychologist engaged in research for 30+ years. She expressed dissatisfaction in our forum that the ALSFRS-R, the “gold standard” measure of ALS function, was insensitive at lower levels. Patients like her, or Stephen Hawking, could be rated a zero in terms of function, despite the fact they could still work, use the computer, and manage their affairs. With her help as a co-investigator, we developed an extension to the ALSFRS-R that is in use today in clinical research.

Participation in Conferences (AMIA)



Nights with ZERO “Deep Sleep (N3)” result in waking the next day feeling “unrefreshed”

Nights with GOOD “REM Sleep (N4)” result in better cognitive function the next day.



Craig Baquet, AMIA 2015 Annual Symposium - 11/15/15

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