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

1. Survey Invitation → PM
   a. Survey Screener (part 1)
      Does pt qualify?
      No → kicked out of survey with note
      Yes → b. Informed Consent
         c. Survey 1 (part 2)
            Thank you note, NOT accepted

2. Mail Welcome Package
   Includes: welcome letter, copy for fitbit flex and device instructions, terms and conditions, authentication instructions, FAQs, Contact information

3. E-mail welcome message
   1. Ideally, Patient sets up device
      2. Ideally, Patient authenticates device
      3. Patient uploads data
      4. PLM receives data

4. Weekly e-mail reminder, hot topics, final reminder
   Includes: Webcast?, Forum discussion instructions, authentication reminders (starts at around week 2 or 3? those who have those who have not, hot topics,

5. Primer email - wrapping up study survey to come

6. Final survey invitation & reminder (general and incompletes)

7. Final Authentication e-mail

8. Thank you

9. Sharing back results
Team of Advisors
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?

Give Data, Get Data

INSOMNIA: HOW LACK OF SLEEP AFFECTS PEOPLE WITH HEALTH CONDITIONS

HAVE YOU BEEN DIAGNOSED WITH INSOMNIA?

- 10% Yes
- 77% No
- Not sure
Give Back

MARIJUANA AS MEDICINE

Side effects of medical marijuana

- Dry Mouth: 39% Mild
- Increased Appetite: 47% None
- Sleepiness: 12% Moderate
- Severe: 2%

As reported on PatientsLikeMe as of June 2015

In conjunction with Dr. David Casarett: “Stoned: A Doctor’s Case for Medical Marijuana”
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.
Are you living with #Crohn's disease? How do your symptoms compare to those reported by PatientLikeMe members? http://bddy.me/2aT1bQu
Are you living with post-traumatic stress? Who helped you seek treatment? [link](http://www.patientslikeme.com) #PTSD #PTS

Living with post-traumatic stress

Seeking treatment

As reported by 697 members of PatientsLikeMe’s post-traumatic stress (PTS) community.

Who helped you seek treatment?

<table>
<thead>
<tr>
<th>TOTAL POPULATION</th>
<th>MILITARY VS. NON-MILITARY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sought treatment on their own</td>
<td>Helped by family or relatives</td>
</tr>
<tr>
<td>41%</td>
<td>MILITARY</td>
</tr>
<tr>
<td>27%</td>
<td>NON-MILITARY</td>
</tr>
</tbody>
</table>

Military = people who indicated they have served in the military.
Non-military = people who indicated they have not served in the military and people who have not.
Factors in Patient Empowerment: A Survey of an Online Patient Research Network

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

Open Access | Original Research Article
First Online: 07 May 2016
DOI: 10.1007/s40271-016-0171-2

Cite this article as:

PLM Publications

Full bibliography with links to articles:
https://www.patientslikeme.com/research/publications
Value of Open Access

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

Emil Chiauzzi, Carlos Rodarte and Pronabesh DasMahapatra

Received: 23 November 2014 | Accepted: 10 March 2015 | Published: 9 April 2015

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
Expanding Your Readership

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

Overview of attention for article published in BMC Medicine, April 2015

Summary

You are seeing a free-to-access but limited selection of the activity Altmetric has collected about this research output. Click here to find out more.

About this Attention Score

In the top 5% of all research outputs scored by Altmetric

Mentioned by

1 blog
133 tweeters
4 Facebook pages
1 Google+ user

Readers on

90 Mendeley

What is this page?

Geographical breakdown

<table>
<thead>
<tr>
<th>Country</th>
<th>Count</th>
<th>At %</th>
</tr>
</thead>
<tbody>
<tr>
<td>United States</td>
<td>40</td>
<td>30%</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>24</td>
<td>18%</td>
</tr>
<tr>
<td>Spain</td>
<td>7</td>
<td>5%</td>
</tr>
<tr>
<td>Canada</td>
<td>4</td>
<td>3%</td>
</tr>
<tr>
<td>Australia</td>
<td>2</td>
<td>2%</td>
</tr>
<tr>
<td>Netherlands</td>
<td>2</td>
<td>2%</td>
</tr>
<tr>
<td>France</td>
<td>2</td>
<td>2%</td>
</tr>
<tr>
<td>Colombia</td>
<td>2</td>
<td>2%</td>
</tr>
<tr>
<td>Greece</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>Other</td>
<td>8</td>
<td>6%</td>
</tr>
<tr>
<td>Unknown</td>
<td>41</td>
<td>31%</td>
</tr>
</tbody>
</table>

https://www.altmetric.com/details/3890414
Patient Profiles in Publications
Patients as Coauthors

Increasing Patient Involvement in Drug Development

Maria M. Lowe, PharmD, BCPS1,4, David A. Blaser, PharmD3, Lisa Cone, BA, Steve Arcona, PhD2, John Ko, PharmD, MS2, Rahul Sasane, PhD2, Paul Wicks, PhD1

1 PatientsLikeMe, Cambridge, MA, USA; 2 Novartis 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.

Copyright © 2016, International Society for Pharmacoeconomics and Outcomes Research (ISPOR). Published by Elsevier Inc. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).
Tam Builds a New Health Measure

https://www.youtube.com/watch?v=JrWOOiixr9o
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.

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
Category: More Research
News Organization: European Journal of Neurology
Source URL: http://www.ncbi.nlm.nih.gov/pubmed/19364363

http://www.brownalumnimagazine.com/content/view/2218/40/
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
Emil Chiauzzi, Ph.D.
Research Director
echiauzzi@patientslikeme.com