Crowdsourcing Patient Medical Data: Opportunities and Innovations

June 30, 2016 | MUHC-ISAI Research Symposium

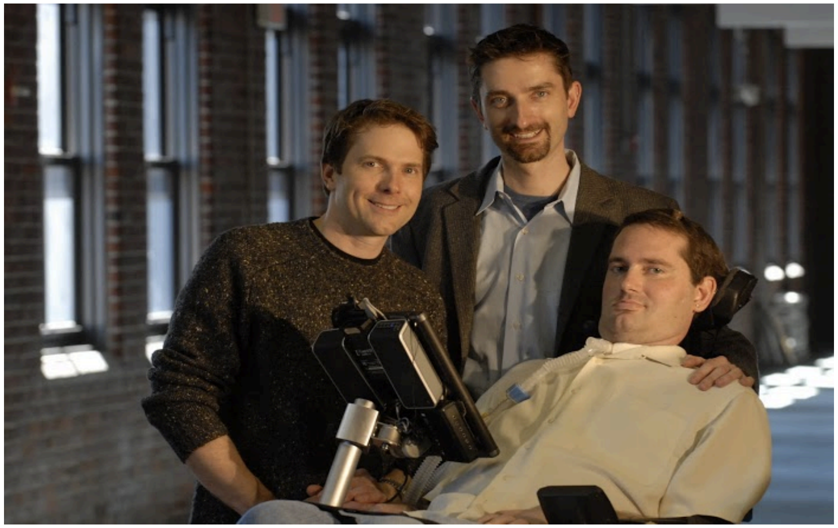
Emil Chiauzzi, PhD
Research Director | PatientsLikeMe

What is PatientsLikeMe?

About PatientsLikeMe

Our mission is to improve the lives of patients through new knowledge derived from shared real-world experiences and outcomes

- Founded in 2004 as a direct response to their family's experience with chronic disease
- It is an online, open, patient-facing community for patients with life changing diseases
- Started in ALS in 2004 and expanded to all conditions in 2011. Deep patient data and experience in 30-40 chronic diseases
- Bringing together an ecosystem of forward thinking healthcare partners



PatientsLikeMe at a Glance

Patients

- 400,000+ patients
- 2,500+ conditions

Data

- 30+ million structured data points
- 3+ million free-text posts
- 15+ PROs

Insights

- 70+ publications, most peer reviewed
- Patient-generated taxonomy
- Safety monitoring platform
- Endpoints in clinical trials

patientslikeme®

Commercial & Partner Research

Development of a Scale to Measure Barriers to Disease-Modifying Therapy Adherence in MS

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Background

- Patients with MS must regularly take disease modifying therapies (DMTs) to reduce the frequency of relapses and progression of disability
- Most DMTs are needle-based, which may present a range of barriers to being fully adherent
- Poorer adherence may lead to poorer outcomes in MS; therefore we sought to understand the impact of different barriers to adherence across existing DMTs
- The existing literature uses imprecise measures of adherence:
  - Medication Possession Ratio (MPR) only records whether a DMT prescription was filled, not whether they actually took the treatment
  - Defining "non-adherent" patients as missing a single dose in the past month means something different for patients on a daily injection (e.g. glatiramer acetate) than patients on a weekly injection (e.g. IFB-1a IM).
  - Counting missed doses without reference to the number of prescribed doses poses the same problem

Objectives

1. To quantify the degree of non-adherence across patients with different daily dosing regimes
2. To develop a self-report questionnaire to quantify the differing profiles of barriers to adherence – The MS Treatment Adherence Questionnaire (MS-TAQ)

Methods

- MS-TAQ was developed via review of the scientific literature, text analysis of the MS forum on PatientsLikeMe.com, and cognitive debriefing of the pilot instrument
- PatientsLikeMe Lens™ survey developed to find out more about the experiences of MS patients
- MS-TAQ consisted 13 items on barriers to adherence, 10 questions on side effects, 7 items on coping methods used to moderate SE's. The survey was sent out to 1,209 MS patient members; 5 blocks of 200 on each DMT plus 200 on no DMT.

December 2009
1,209 invites sent

445 Complete responses
(Response Rate: 37%)

442 Complete responses

3 Novatrone patients excluded

429 Complete responses

13 Patients excluded for poor DMT data

100 GA (23%)
86 IFB-1a IM (20%)
81 IFB-1a SC (18%)
63 IFB-1b SC (14%)
58 Natal. (14%)
41 No DMT (9%)

Figure 1: Recruitment flow of participants

DMT (Typical dosing)	N	Age (SD)	% Female	First DMT?	Median DMT Duration	N Missing Any Dose in Past 28 Days (%)	Median Missed Dose Ratio in Patients Missing A Dose (range)	Mean MS Time since onset, yrs	Mean MS Time since diagnosis, yrs
GA (Daily)	100	47 (11)	84%	72%	25m	51 (51%)	12% (4-71%)	10 (9)	6 (7)
IFB-1a IM (Weekly)	86	48 (11)	78%	84%	22m	14 (16%)	25% (22-100%)	11 (10)	7 (7)
IFB-1a SC (Every 3 days)	81	44 (10)	75%	62%	22m	25 (31%)	17% (7-100%)	7 (8)	5 (6)
IFB-1b SC (Alternate days)	63	47 (9)	90%	75%	25m	31 (49%)	15% (7-100%)	11 (10)	8 (8)
Natalizumab (Monthly)	58	45 (10)	72%	5%	16m	5 (8%)	N/A*	15 (9)	11 (7)
No DMT (N/A)	41	48 (11)	73%	n/a	n/a	N/A	N/A	14 (9)	10 (7)
Overall	429	46 (10)	79%	59%	22m	31%	17%	11 (9)	7 (7)

Table 1: Demographic characteristics of MS-TAQ validation sample, *MDR not calculated for Natalizumab as some patients reported decreasing their dosage frequency due to safety concerns, rendering 28-day window inappropriate

MS-TAQ Barriers % "Moderately" or "Extremely Important"

Did Not Feel Like Taking	38%
Tired of Taking DMT	33%
Memory Problems	35%
Too Busy	32%
SE's of Injection	27%
SE's of Medication	22%
Anxious About DMT	19%
DMT Interfered w/ life	18%
Dissatisfaction w/ DMT	13%
In transit, DMT at home	11%
Ran Out of DMT	11%
Needed Help Taking DMT	10%
Fear of Needles	9%

Among patients who mis one dose in the past 28 point change on the MST scale = a 10% increase in ratio

MS:

Among patients who mis one dose in the past 28 da change on the MSTAC Strategies scale = a 4% missed dose rat

MS-TAQ Coping Strategies % Endorsing: "Yes, I usually did this"

MS-TAQ Side Effects % Endorsing "Most" or "All of the time"

Figure 2: Positive and negative influe

Results

Participants

- Patients were comparable across DMTs on age, sex, and disability using a self-report measure of function, the MS Rating Scale (MSRS, p>0.05).
- There were significant between-group differences for BMI (F(5,417)=3.417 p=0.005), DMT duration (χ^2(28)=45.176, p=0.021), time since MS diagnosis (F(5,417)=6.888, p<0.001), time since MS onset (F(5,420)=5.841, p<0.001), and disease type (χ^2(25)=43.052, p=0.014).

Missing Any Dose in Past 28 Days

- Between 8-51% of patients reported missing at least one dose of their DMT in the previous 28 days, with significant between-group differences (χ2(4)=63.022, p=<0.001).
- Multivariate analysis showed no significant impact on likelihood of missing at least one dose for age, sex, BMI, symptom severity, time on current DMT, time since symptom onset, time since diagnosis, or problems grasping the injector.

Missed Dose Ratio in Past 28 Days

- Among patients who missed a dose, the Missed Dose Ratio (MDR) varied significantly by treatment

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ScienceDirect
journal homepage: www.elsevier.com/locate/jval

COMMENTARY

Can We Use Social Media to Support Content Validity of Patient-Reported Outcome Instruments in Medical Product Development?

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ABSTRACT

We report a panel designed to open a dialog between pharmaceutical sponsors, regulatory reviewers, and other stakeholders regarding the use of social media to collect data to support the content validity of patient-reported outcome instruments in the context of medical product labeling. Multiple stakeholder perspectives were brought together to better understand the issues encountered in pursuing social media as a form of data collection to support content validity. Presenters represented a pharmaceutical sponsor of clinical trials, a regulatory reviewer from the Food and Drug Administration, and an online data platform provider. Each presenter shared its perspective on the advantages and disadvantages of using social media to collect this type of information. There was consensus that there is great potential for using social media for this purpose. There remain, however, unanswered questions that need to be addressed such as identifying which type of social media is most appropriate for data collection and ensuring that participants are representative of the target population while maintaining the advantages of anonymity provided by online platforms. The use of social media to collect evidence of content validity holds much promise. Clarification of issues that need to be addressed and accumulation of empirical evidence to address these questions are essential to moving forward.

Keywords: clinical trials, online communities, patient-reported outcomes, social media.

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Introduction

Patient-reported outcomes (PROs) are increasingly recognized as important tools in adding value to the drug review and evaluation process [1] because they provide unique perspectives on medical conditions or their therapies that are known only to the patient [2]. "Content validity" describes the extent to which a

and response options through cognitive debriefing [5]. Best practices usually include either individual interviews or focus groups with participants who are experiencing the target condition or have recent experience with it. These traditional methods of collecting qualitative data to support the content validity of a new or existing PRO instrument, however, are labor intensive, time consuming, and relatively expensive. Although

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ORIGINAL RESEARCH ARTICLE

Quality of Life in Organ Transplant R in an Online Transplant Community

Paul Wicks · Katherine A. Sulham · Ari Gnanasakthy

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Abstract

Background The PatientsLikeMe Organ Transplants online community allows patients to share detailed health information for research.
Objectives The objectives of our study were to describe and contrast data collected through an online community with the broader organ transplant population.
Methods Quantitative data were examined with respect to basic demographic characteristics and quantitative data including treatment, symptoms, side effects, and the PatientsLikeMe Quality of Life (PLMQOL) scale. Qualitative data including forum discussion posts and treatment evaluations were examined to support future development of standardized questions that could be added to the platform. Online data were compared with US national registry data from the United Network for Organ Sharing (UNOS).
Results Within 30 days of account creation, 1,924 single-organ transplant patients provided spontaneous, patient-reported data in the form of 915 reported symptoms, 938

with epilepsy, fibromyalgia, mood disorders, Parkinson's disease, multiple sclerosis, or ALS. Site users generated 2,169 posts to 346 unique topic threads in the transplants forum.
Conclusions Organ transplant patients are willing to report detailed health data through online communities across key domains—symptoms, treatment effects, and generic quality of life—that constitute the essential core of patient-reported outcomes. Patient-reported outcomes captured online have the potential to accelerate learning about patient experiences but suffer methodological challenges that must be overcome to maximize their utility.

Key Points for Decision Makers

- The Internet is no longer just where patients go to read leaflets or chat in forums, they are using the same tools used in clinical research studies to learn more about managing their disease and contribute to research.
- The number of patients online today is relatively small

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Academic Research and Nonprofits

University of Michigan
Medical School

ALS untangled

Food and Drug Administration

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SCHOOL OF PHARMACY

National Kidney Foundation
Serving NEW ENGLAND

the schwartz center
FOR COMPASSIONATE HEALTHCARE

Robert Wood Johnson Foundation

USF
HEALTH

NIH
National Institute
of Mental Health

KING'S College
LONDON

Duke
ALS Clinic

ONE MIND

ORION
BIONETWORKS

https://www.patientslikeme.com/about/partners

Who Joins PatientsLikeMe?

PatientsLikeMe Members

- 70% Female
- 16% non-Caucasian
- 40s-50s
- Chronic diseases
- Multiple comorbidities
- English-speaking
- 60% US
- Canada: 13,237

Conditions on PLM

Neurological and brain

- Multiple Sclerosis (48,187)
- Parkinson's Disease (11,940)
- Epilepsy (9,944)
- Migraine (8,365)
- ALS (Amyotrophic Lateral Sclerosis) (8,141)

Muscle, bone, and joint

- Fibromyalgia (62,220)
- Rheumatoid Arthritis (RA) (9,207)
- Systemic Lupus Erythematosus (18,124)
- Osteoarthritis (5,261)
- Degenerative Disc Disease (3,496)

Mental health

- Major Depressive Disorder (21,511)
- Generalized Anxiety Disorder (18,755)
- Post-traumatic stress disorder (14,735)
- Panic Disorder (10,112)
- Social Anxiety Disorder (6,022)

Metabolism and nutrition

- Diabetes Type 2 (18,156)
- Diabetes Type 1 (2,473)
- Obesity (2,099)
- High Cholesterol (Hypercholesterolemia) (1,921)
- Vitamin D Deficiency (1,681)

Gastrointestinal

- IBS (Irritable Bowel Syndrome) (4,872)
- GERD (Gastroesophageal reflux disease) (4,215)
- Crohn's Disease (4,023)
- Ulcerative colitis (1,234)
- Celiac Disease (828)

Respiratory

- Asthma (5,855)
- Idiopathic Pulmonary Fibrosis (5,457)
- COPD (Chronic Obstructive Pulmonary Disease) (2,349)
- Sleep Apnea Disorder (1,909)
- Cystic Fibrosis (1,237)

Oncology

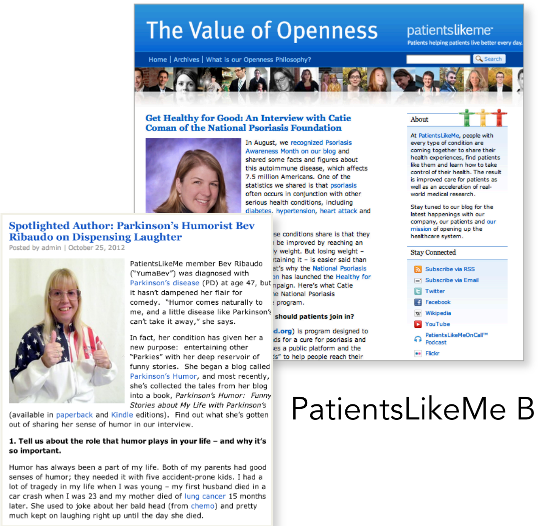
- Lung Cancer (4,020)
- Multiple Myeloma (2,580)
- Breast Cancer (1,673)
- Prostate Cancer (827)
- Colon Cancer (428)

Cross-disease symptoms

- Anxious mood (115,512)
- Depressed Modd (116,211)
- Fatigue (117,668)
- Pain (114,463)
- Insomnia (104,507)

Patient Outreach

- Facebook, Twitter, banner ads
- Search engine optimization
- KOL outreach
- Partnerships with targeted non-profits
- Blogs and support groups



The Value of Openness

patientslikeme

Patients helping patients live better every day.

Home | Archives | What is our Openness Philosophy?

Search

Get Healthy for Good: An Interview with Catie Coman of the National Psoriasis Foundation

In August, we recognized Psoriasis Awareness Month on our blog and shared some facts and figures about this autoimmune disease, which affects 7.5 million Americans. One of the statistics we shared is that psoriasis often occurs in conjunction with other serious health conditions, including diabetes, hypertension, heart attack and

About

At PatientsLikeMe, people with every type of condition are coming together to share their health experiences, find patients like them and learn how to take control of their health. The result is improved care for patients as well as an acceleration of real-world medical research.

Stay tuned to our blog for the latest happenings with our company, our patients and our mission of opening up the healthcare system.

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Spotlighted Author: Parkinson's Humorist Bev Ribaudo on Dispensing Laughter

Posted by admin | October 25, 2012

PatientsLikeMe member Bev Ribaudo ("YumaBev") was diagnosed with Parkinson's disease (PD) at age 47, but it hasn't dampened her flair for comedy. "Humor comes naturally to me, and a little disease like Parkinson's can't take it away," she says.

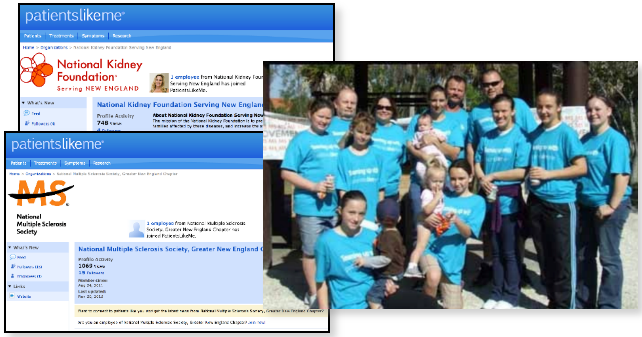
In fact, her condition has given her a new purpose: entertaining other "Parkies" with her deep reservoir of funny stories. She began a blog called Parkinson's Humor, and most recently, she's collected the tales from her blog into a book, *Parkinson's Humor: Funny Stories about My Life with Parkinson's* (available in paperback and Kindle editions). Find out what she's gotten out of sharing her sense of humor in our interview.

1. Tell us about the role that humor plays in your life – and why it's so important.

Humor has always been a part of my life. Both of my parents had good senses of humor; they needed it with five accident-prone kids. I had a lot of tragedy in my life when I was young – my first husband died in a car crash when I was 23 and my mother died of lung cancer 15 months later. She used to joke about her bald head (from chemo) and pretty much kept on laughing right up until the day she died.

PatientsLikeMe Blog

Non-Profit Pages



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Patients | Treatments | Symptoms | Research

Home > Organizations > National Kidney Foundation Serving New England

National Kidney Foundation Serving NEW ENGLAND

1 employee from National Kidney Foundation Serving New England has joined PatientsLikeMe.

What's New

National Kidney Foundation Serving New England

Profile Activity

748 Views

About National Kidney Foundation Serving New England

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Home > Organizations > National Multiple Sclerosis Society, Greater New England Chapter

National Multiple Sclerosis Society

1 employee from National Multiple Sclerosis Society, Greater New England Chapter has joined PatientsLikeMe.

What's New

Feed

Followers (15)

Employees (1)

Links

Website

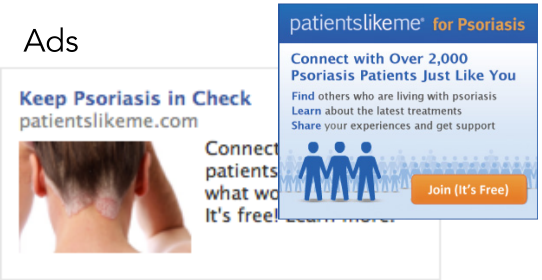
National Multiple Sclerosis Society, Greater New England Chapter

Profile Activity

1069 Views

15 Followers

Ads



Keep Psoriasis in Check

patientslikeme.com

patientslikeme for Psoriasis

Connect with Over 2,000 Psoriasis Patients Just Like You

Find others who are living with psoriasis

Learn about the latest treatments

Share your experiences and get support

What Do Members Do?

Democratization of Information

yelp

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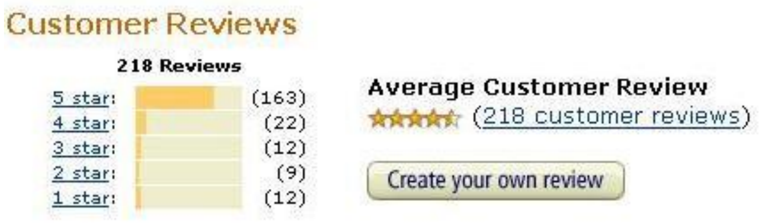

Customer Reviews

218 Reviews

5 star:	(163)
4 star:	(22)
3 star:	(12)
2 star:	(9)
1 star:	(12)

Average Customer Review
★★★★☆ (218 customer reviews)

Create your own review

amazon

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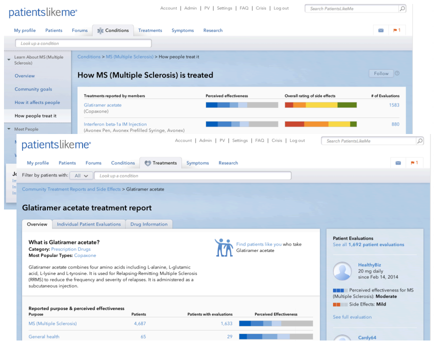
What Members Do

Learn

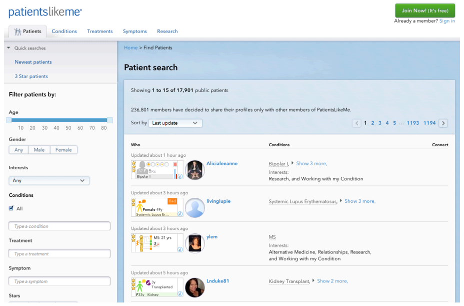
about living with and treating life-changing conditions



- Answer the question “Is this *normal?”*
- Learn from aggregated patient treatment and symptom data

Connect

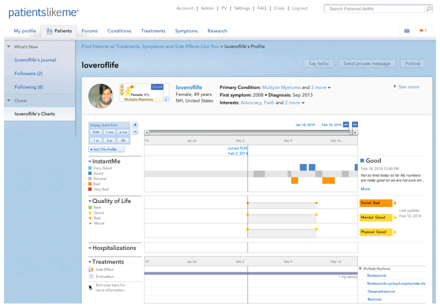
with others sharing those experiences



- Search patients based on age, gender, disease, treatment, symptoms, interests, etc.
- Day-to-day support
- Live better, together

Track

their history and progress over time



- Document changes to symptoms and new treatments, triggers and side effects
- Generate real-world outcomes research data

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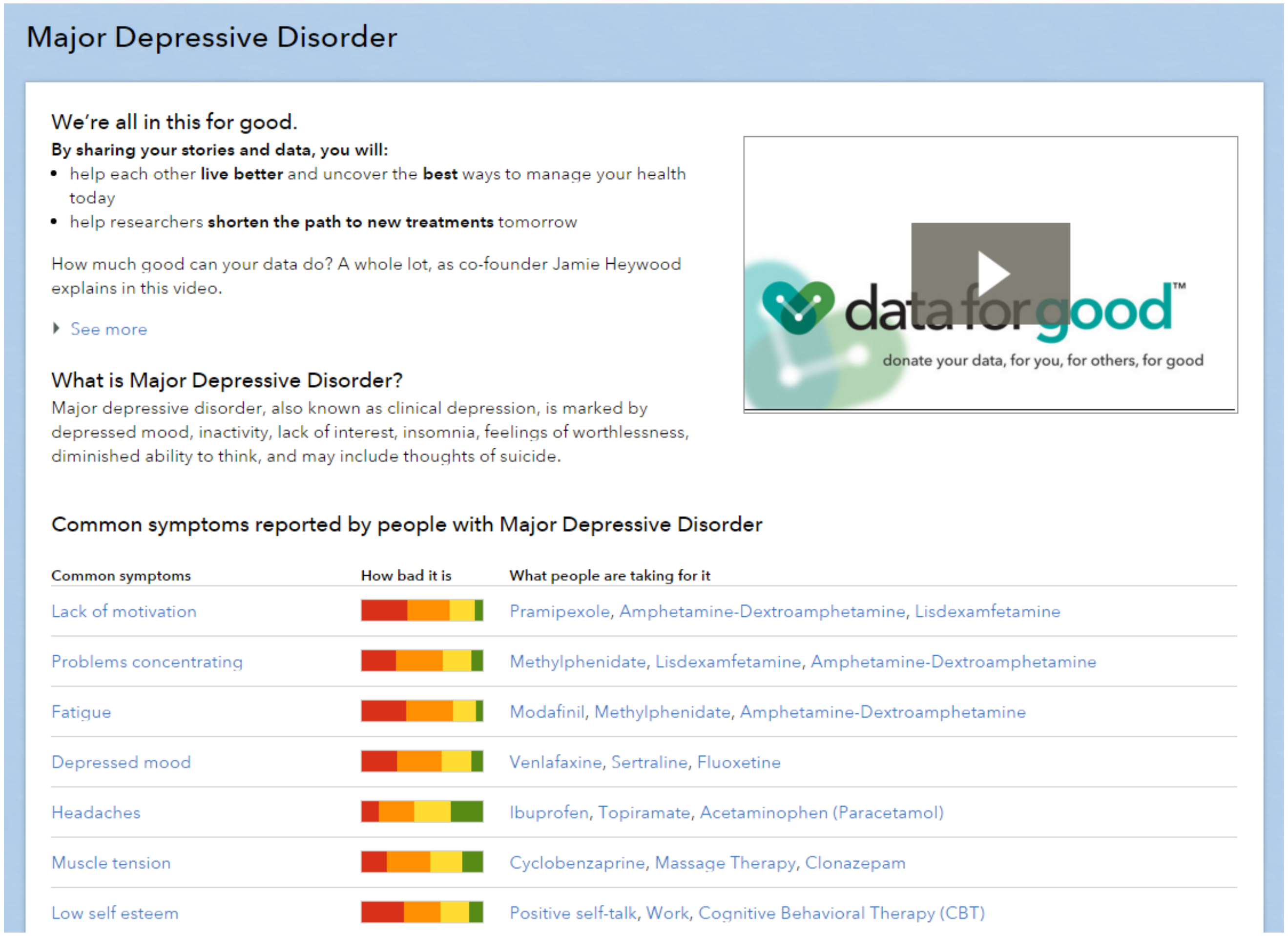
LEARN …



Major Depressive Disorder

We're all in this for good.

By sharing your stories and data, you will:

- help each other **live better** and uncover the **best** ways to manage your health today
- help researchers **shorten the path to new treatments** tomorrow

How much good can your data do? A whole lot, as co-founder Jamie Heywood explains in this video.

▸ See more

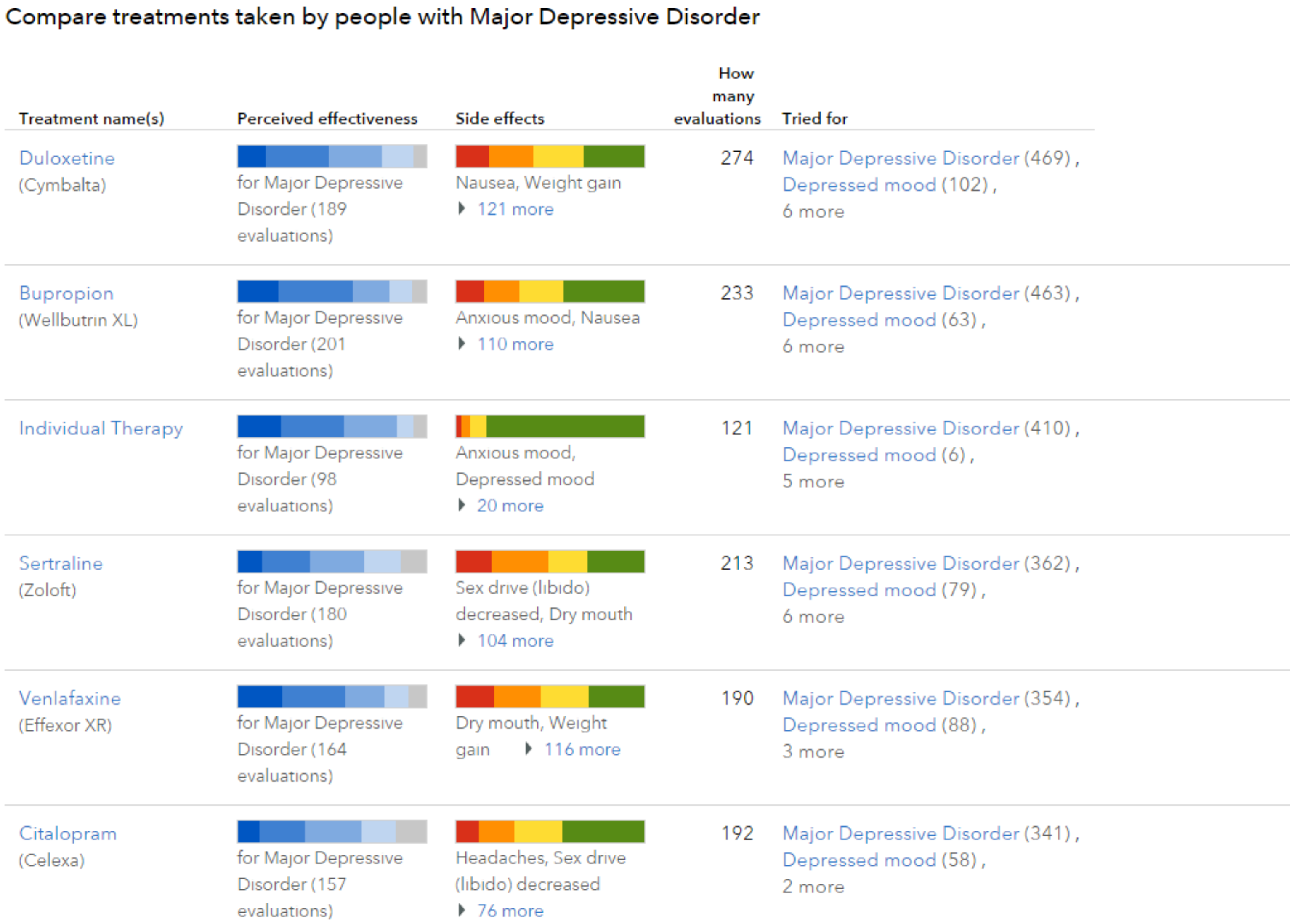
What is Major Depressive Disorder?

Major depressive disorder, also known as clinical depression, is marked by depressed mood, inactivity, lack of interest, insomnia, feelings of worthlessness, diminished ability to think, and may include thoughts of suicide.

Common symptoms reported by people with Major Depressive Disorder

Common symptoms	How bad it is	What people are taking for it
Lack of motivation	🟥🟧🟨🟩	Pramipexole, Amphetamine-Dextroamphetamine, Lisdexamfetamine
Problems concentrating	🟥🟧🟨🟩	Methylphenidate, Lisdexamfetamine, Amphetamine-Dextroamphetamine
Fatigue	🟥🟧🟨🟩	Modafinil, Methylphenidate, Amphetamine-Dextroamphetamine
Depressed mood	🟥🟧🟨🟩	Venlafaxine, Sertraline, Fluoxetine
Headaches	🟥🟧🟨🟩	Ibuprofen, Topiramate, Acetaminophen (Paracetamol)
Muscle tension	🟥🟧🟨🟩	Cyclobenzaprine, Massage Therapy, Clonazepam
Low self esteem	🟥🟧🟨🟩	Positive self-talk, Work, Cognitive Behavioral Therapy (CBT)

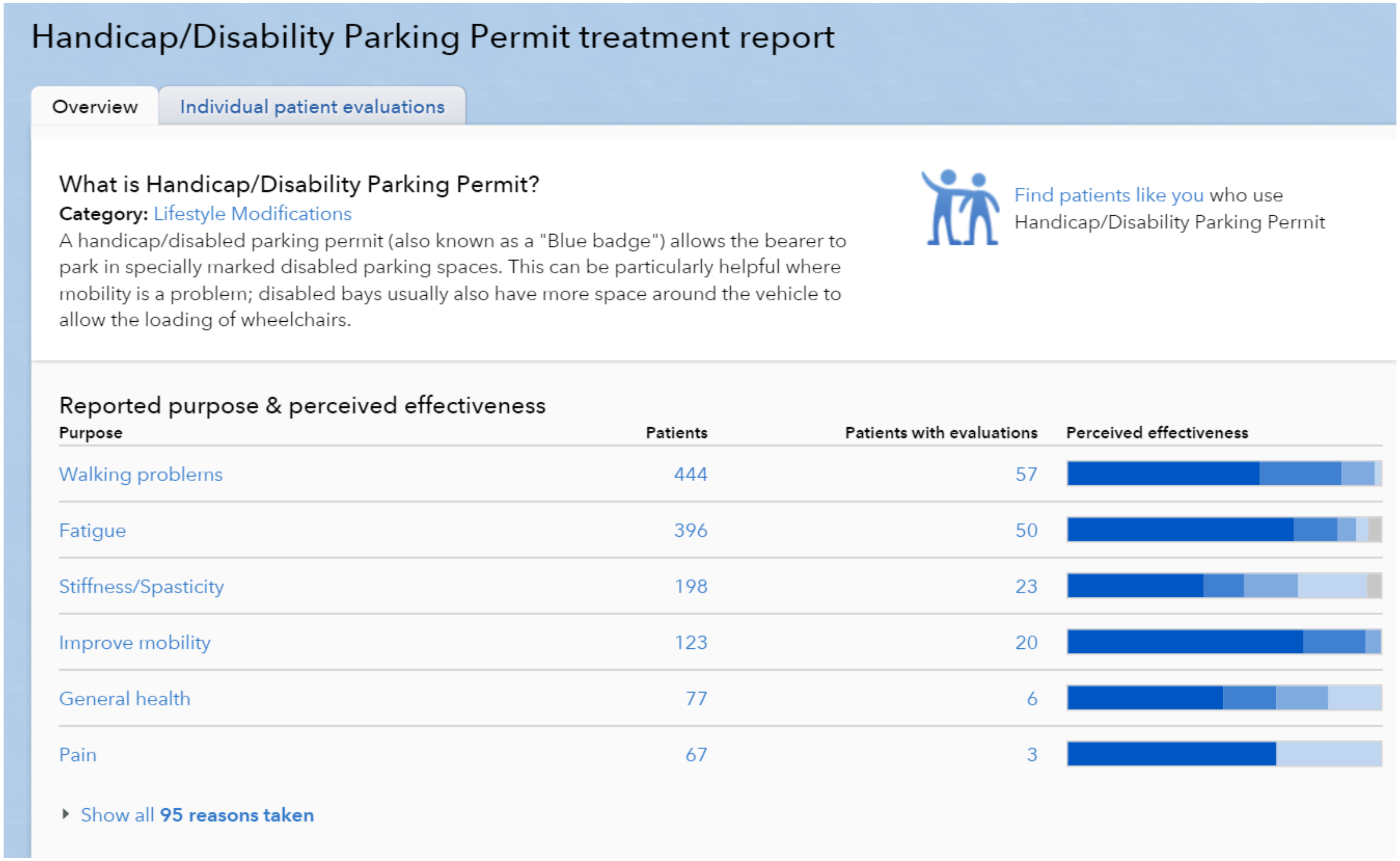
… what treatments others are receiving…



Compare treatments taken by people with Major Depressive Disorder

Treatment name(s)	Perceived effectiveness	Side effects	How many evaluations	Tried for
Duloxetine (Cymbalta)	for Major Depressive Disorder (189 evaluations)	Nausea, Weight gain ▸ 121 more	274	Major Depressive Disorder (469) , Depressed mood (102) , 6 more
Bupropion (Wellbutrin XL)	for Major Depressive Disorder (201 evaluations)	Anxious mood, Nausea ▸ 110 more	233	Major Depressive Disorder (463) , Depressed mood (63) , 6 more
Individual Therapy	for Major Depressive Disorder (98 evaluations)	Anxious mood, Depressed mood ▸ 20 more	121	Major Depressive Disorder (410) , Depressed mood (6) , 5 more
Sertraline (Zoloft)	for Major Depressive Disorder (180 evaluations)	Sex drive (libido) decreased, Dry mouth ▸ 104 more	213	Major Depressive Disorder (362) , Depressed mood (79) , 6 more
Venlafaxine (Effexor XR)	for Major Depressive Disorder (164 evaluations)	Dry mouth, Weight gain ▸ 116 more	190	Major Depressive Disorder (354) , Depressed mood (88) , 3 more
Citalopram (Celexa)	for Major Depressive Disorder (157 evaluations)	Headaches, Sex drive (libido) decreased ▸ 76 more	192	Major Depressive Disorder (341) , Depressed mood (58) , 2 more

A broader view of "treatments" …



Handicap/Disability Parking Permit treatment report

What is Handicap/Disability Parking Permit?

Category: Lifestyle Modifications

A handicap/disabled parking permit (also known as a "Blue badge") allows the bearer to park in specially marked disabled parking spaces. This can be particularly helpful where mobility is a problem; disabled bays usually also have more space around the vehicle to allow the loading of wheelchairs.

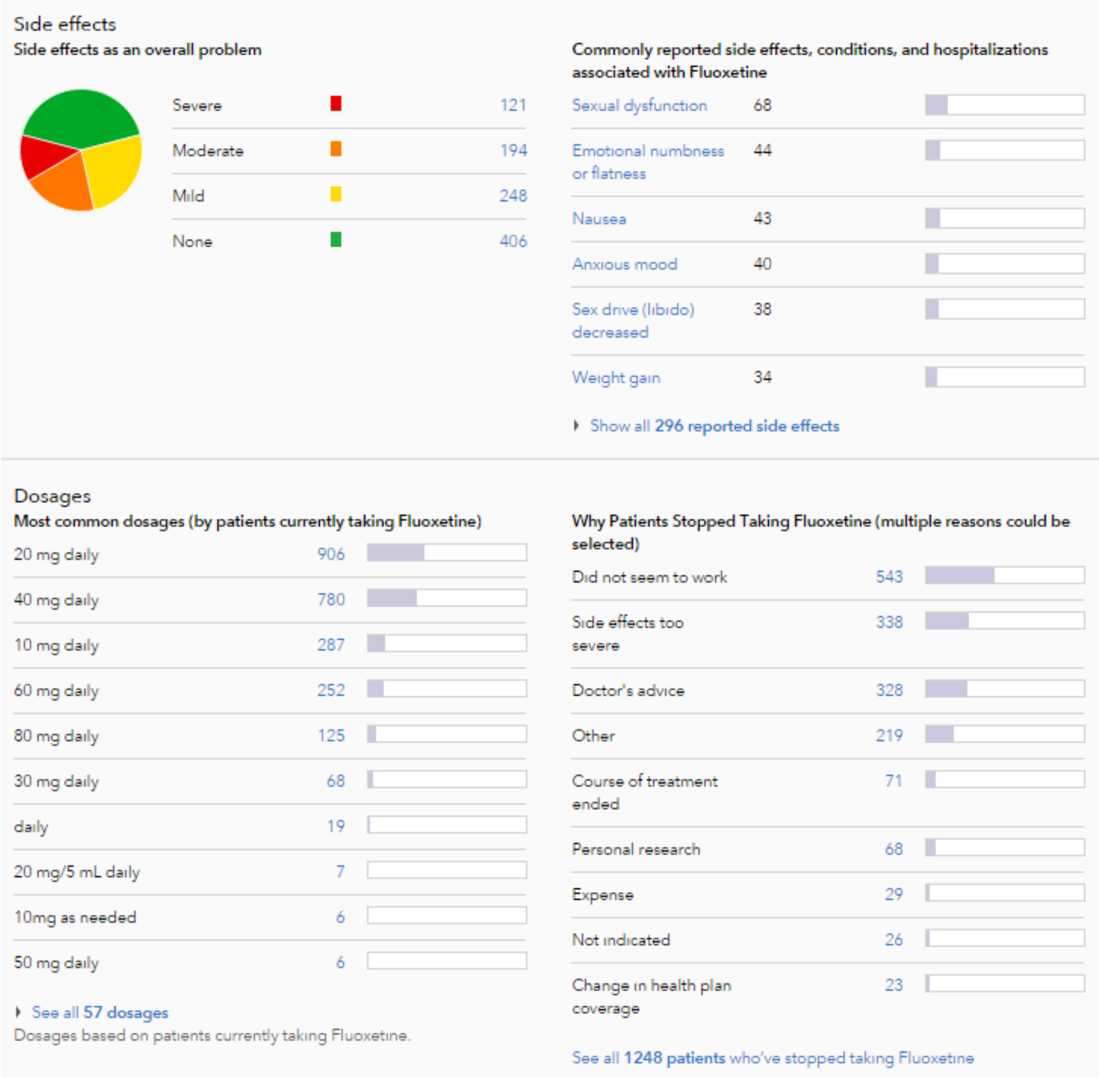
Find patients like you who use Handicap/Disability Parking Permit

Reported purpose & perceived effectiveness

Purpose	Patients	Patients with evaluations	Perceived effectiveness
Walking problems	444	57	
Fatigue	396	50	
Stiffness/Spasticity	198	23	
Improve mobility	123	20	
General health	77	6	
Pain	67	3	

▸ Show all **95 reasons taken**

… about side effects



Side effects

Side effects as an overall problem

Severe	🟥	121
Moderate	🟧	194
Mild	🟨	248
None	🟩	406

Commonly reported side effects, conditions, and hospitalizations associated with Fluoxetine

Sexual dysfunction	68
Emotional numbness or flatness	44
Nausea	43
Anxious mood	40
Sex drive (libido) decreased	38
Weight gain	34

Show all **296 reported side effects**

Dosages

Most common dosages (by patients currently taking Fluoxetine)

20 mg daily	906
40 mg daily	780
10 mg daily	287
60 mg daily	252
80 mg daily	125
30 mg daily	68
daily	19
20 mg/5 mL daily	7
10mg as needed	6
50 mg daily	6

See all **57 dosages**

Dosages based on patients currently taking Fluoxetine.

Why Patients Stopped Taking Fluoxetine (multiple reasons could be selected)

Did not seem to work	543
Side effects too severe	338
Doctor's advice	328
Other	219
Course of treatment ended	71
Personal research	68
Expense	29
Not indicated	26
Change in health plan coverage	23

See all **1248 patients** who've stopped taking Fluoxetine

CONNECT

"We can do much better fighting the disease as a group than we can as individuals…"

"I feel very excited, humbled and grateful that the information being used from my situation will be able to contribute to research to help other people…"

"Thanks to PLM, I learned about a new treatment my doctor didn't realize was used for MS. I'm on it now and I've never felt better!"

TRACK

- Basic Information (age, sex, etc.)
- Diseases (early signs, diagnosis status, etc.)
- General & Specific Symptoms (onset, severity status, etc.)
- Treatments & Side Effects (Rx, OTC, Supp., non-drug, etc.)
- Quality of Life & Behavior Status (all patients, some disease specific)
- Outcome Measures of Disease (disease dependent)
- Patient-generated narrative text, wearable and sensor data

Engagement

Data Integrity

Standards *

Evidence

Knowledge

Empowerment

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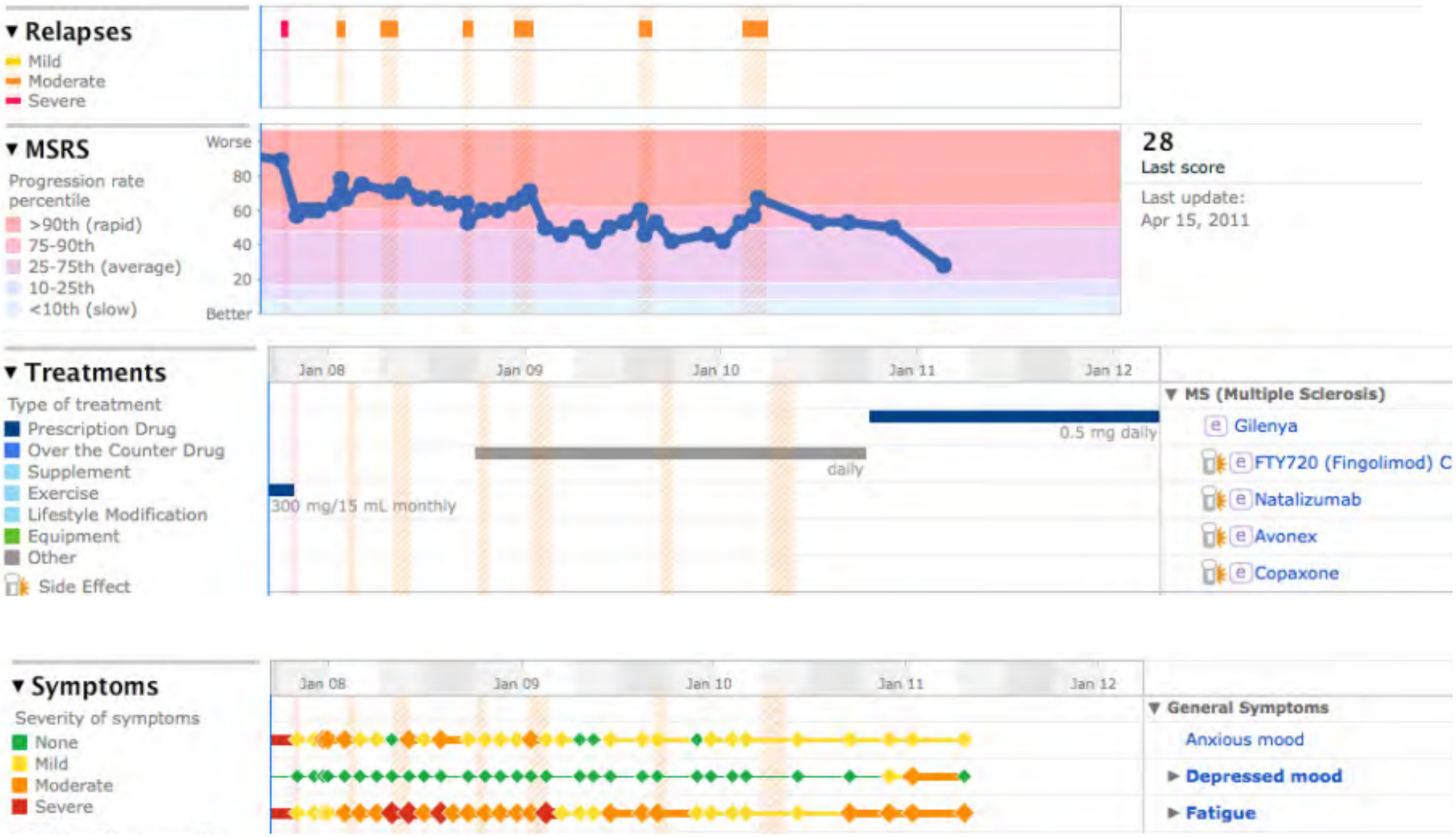
* Patient data mapped to ICD-10, ICF, SNOMED, MedDRA, RxNorm

Multiple Sclerosis Patient Profile


▼ Relapses
Mild
Moderate
Severe
▼ MSRS
Progression rate percentile
>90th (rapid)
75-90th
25-75th (average)
10-25th
<10th (slow)
Worse
80
60
40
20
Better
28
Last score
Last update:
Apr 15, 2011
▼ Treatments
Type of treatment
Prescription Drug
Over the Counter Drug
Supplement
Exercise
Lifestyle Modification
Equipment
Other
Side Effect
Jan 08
Jan 09
Jan 10
Jan 11
Jan 12
0.5 mg daily
daily
300 mg/15 mL monthly
▼ MS (Multiple Sclerosis)
e Gilenya
e FTY720 (Fingolimod) C
e Natalizumab
e Avonex
e Copaxone
▼ Symptoms
Severity of symptoms
None
Mild
Moderate
Severe
Jan 08
Jan 09
Jan 10
Jan 11
Jan 12
▼ General Symptoms
Anxious mood
▶ Depressed mood
▶ Fatigue

How is Research Conducted?

Research as a Journey

“Out of box” experience

Research protocol design

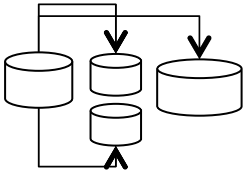
Product enhancements

Study participant selection

Dedicated patient point of contact

Approved
NEW ENGLAND INSTITUTIONAL REVIEW BOARD
IRB

IRB review



Data architecture design

Study execution

Tailored communications

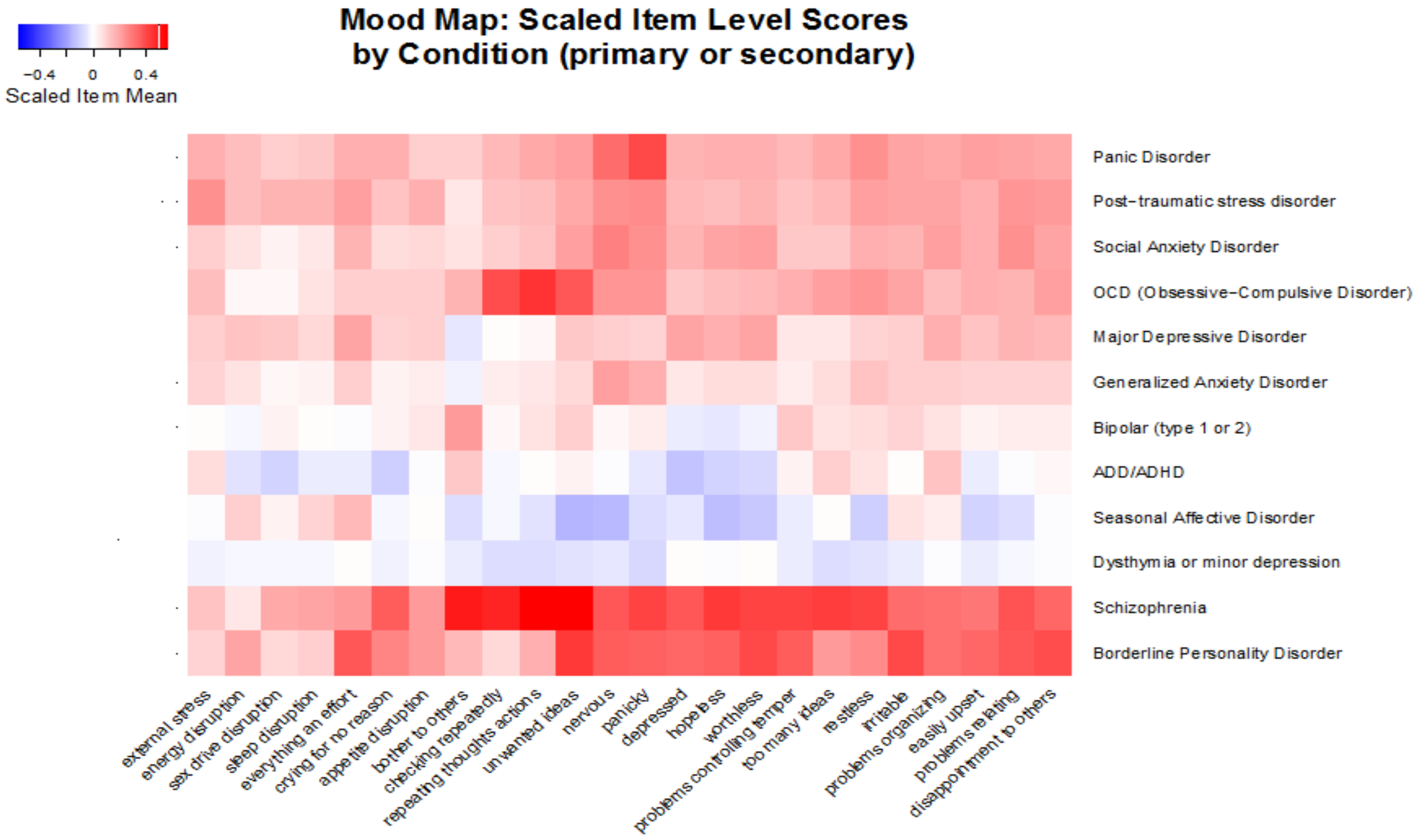
Informed consent

BEST BUY
100

Device procurement

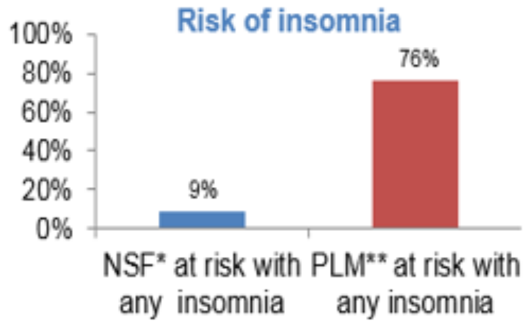
Insight generation

Database Analysis

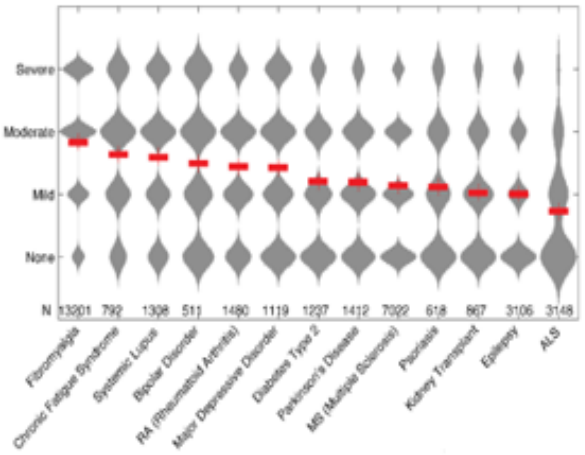


Mood Map: Scaled Item Level Scores by Condition (primary or secondary)

Surveys: Supplemental Data Collection


Risk of insomnia

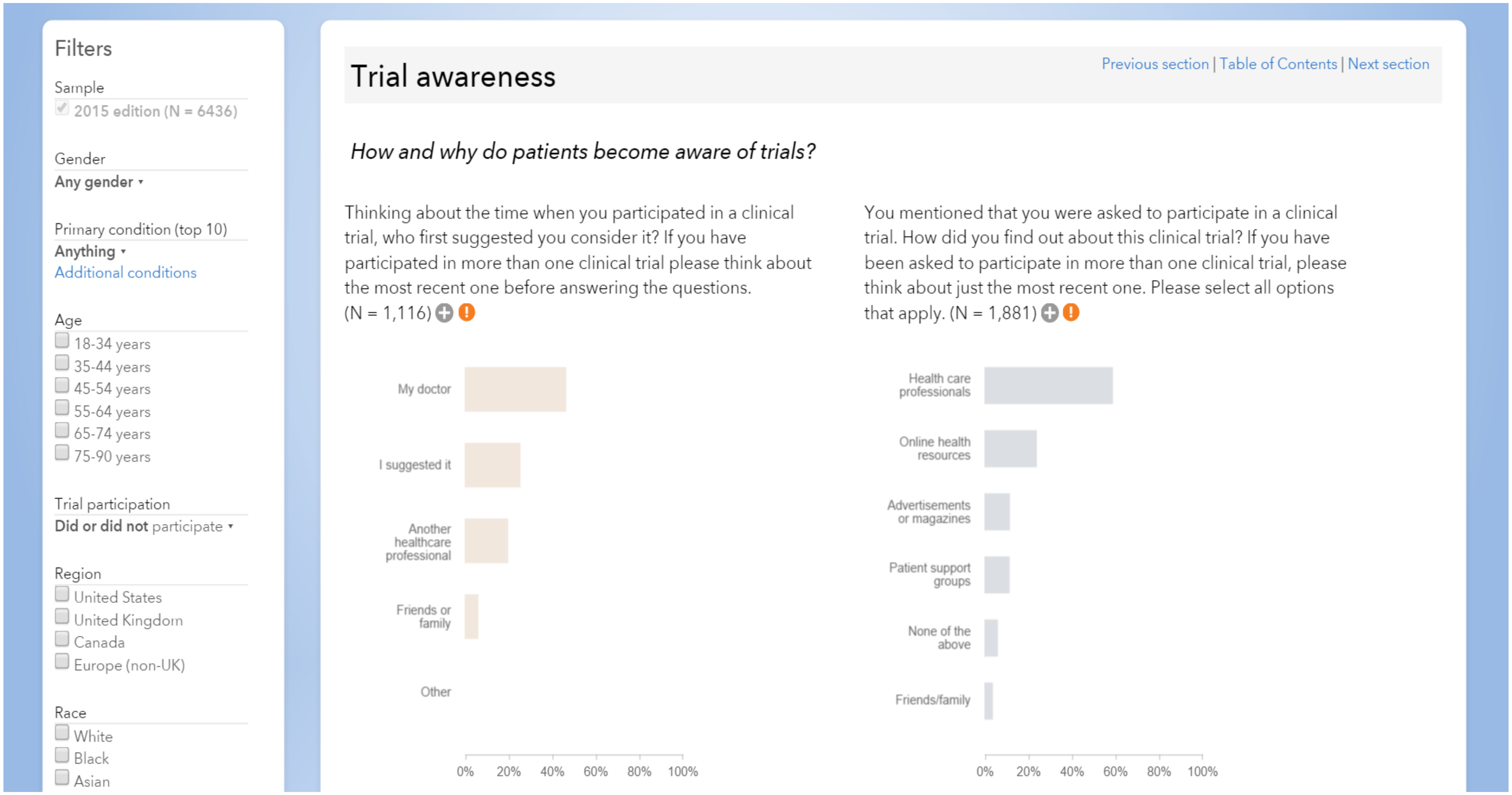
Condition specific insomnia occurrence



- Three quarters of US-based PLM respondents were at risk for National Sleep Foundation (NSF)-defined insomnia.
- Trouble falling asleep was the sleep symptom most likely to result in self-reporting insomnia.
- Forty-four percent awaken during the night and 42% awake unrefreshed, but these symptoms receive less attention.
- Insomnia was worse in fibromyalgia (92%), Crohn's disease (88%), depression (85%), and rheumatoid arthritis (RA) (85%).
- Only 34% of patients reporting severe insomnia had ever received an insomnia diagnosis.

Katic et al. New approach for analyzing self-reporting of insomnia symptoms reveals a high rate of comorbid insomnia across a wide spectrum of chronic diseases. Sleep Medicine, 16(11), November 2015, Pages 1332–1341.

Global Trial Access Databank



Filters

Sample
☑ 2015 edition (N = 6436)

Gender
Any gender ▾

Primary condition (top 10)
Anything ▾
Additional conditions

Age
☐ 18-34 years
☐ 35-44 years
☐ 45-54 years
☐ 55-64 years
☐ 65-74 years
☐ 75-90 years

Trial participation
Did or did not participate ▾

Region
☐ United States
☐ United Kingdom
☐ Canada
☐ Europe (non-UK)

Race
☐ White
☐ Black
☐ Asian

Trial awareness

Previous section | Table of Contents | Next section

How and why do patients become aware of trials?

Thinking about the time when you participated in a clinical trial, who first suggested you consider it? If you have participated in more than one clinical trial please think about the most recent one before answering the questions. (N = 1,116)

My doctor
I suggested it
Another healthcare professional
Friends or family
Other
0%
20%
40%
60%
80%
100%

You mentioned that you were asked to participate in a clinical trial. How did you find out about this clinical trial? If you have been asked to participate in more than one clinical trial, please think about just the most recent one. Please select all options that apply. (N = 1,881)

Health care professionals
Online health resources
Advertisements or magazines
Patient support groups
None of the above
Friends/family
0%
20%
40%
60%
80%
100%

Wearable Research: Daily Tracking in MS

AMERICAN ACADEMY OF NEUROLOGY®
aan.com

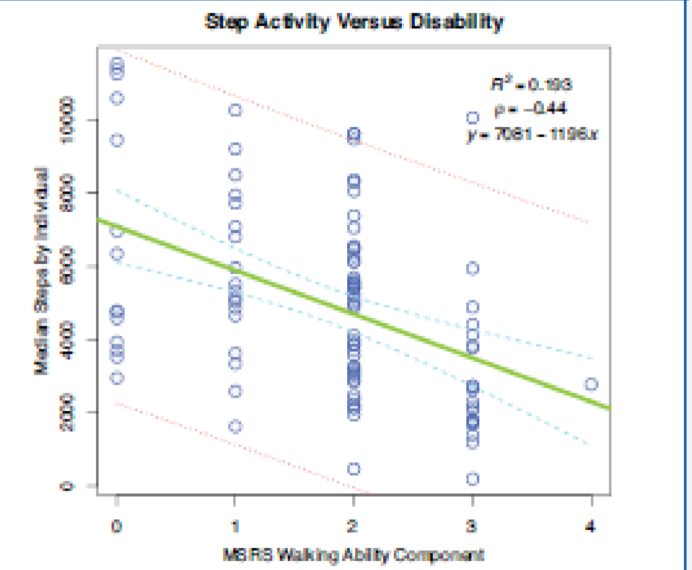
April 21, 2015

- Poster Session III
  - MS and CNS Inflammatory Diseases: Tools for Clinical Assessment and Therapeutic Response

Remote Tracking of Walking Activity in MS Patients in a Real-World Setting (P3.209)

James McIninch[1], Shoibal Datta[1], Pronabesh DasMahapatra[2], Emil Chiauzzi[2], Rishi Bhalerao[2], Alicia Spector[2], Sherrie Goldstein[2], Liz Morgan[2] and Jane Relton[1]

Figure 1. Step Activity Versus Walking Ability



The MSRS score of MS severity is a composite score, a patient self-assessment of MS severity. The component most associated with mobility impairment is the MSRS Walking Ability Component. A value of 0 indicates little or no impairment and higher values indicate progressively more severe impairment. The green line indicated the linear regression; the blue dashed line indicates 95% confidence, and the dotted orange line, 95% prediction confidence.

Goal: understand **utility of consumer activity tracking** device in MS

Feasibility: if we give patients a device, will they use & share data?

248 members of the PLM MS community recruited **within 24 hours**

82% enabled data sharing; mean adherence was 86% (18.2 of 21 days)

Fitbit One™ device shipped to participants with use instructions

Real-time device measures captured on patient profile through API calls

Data analyses were done by **linking member profile, device data and surveys** at baseline and follow-up

Subjective patient-reported data linked to objective device measures

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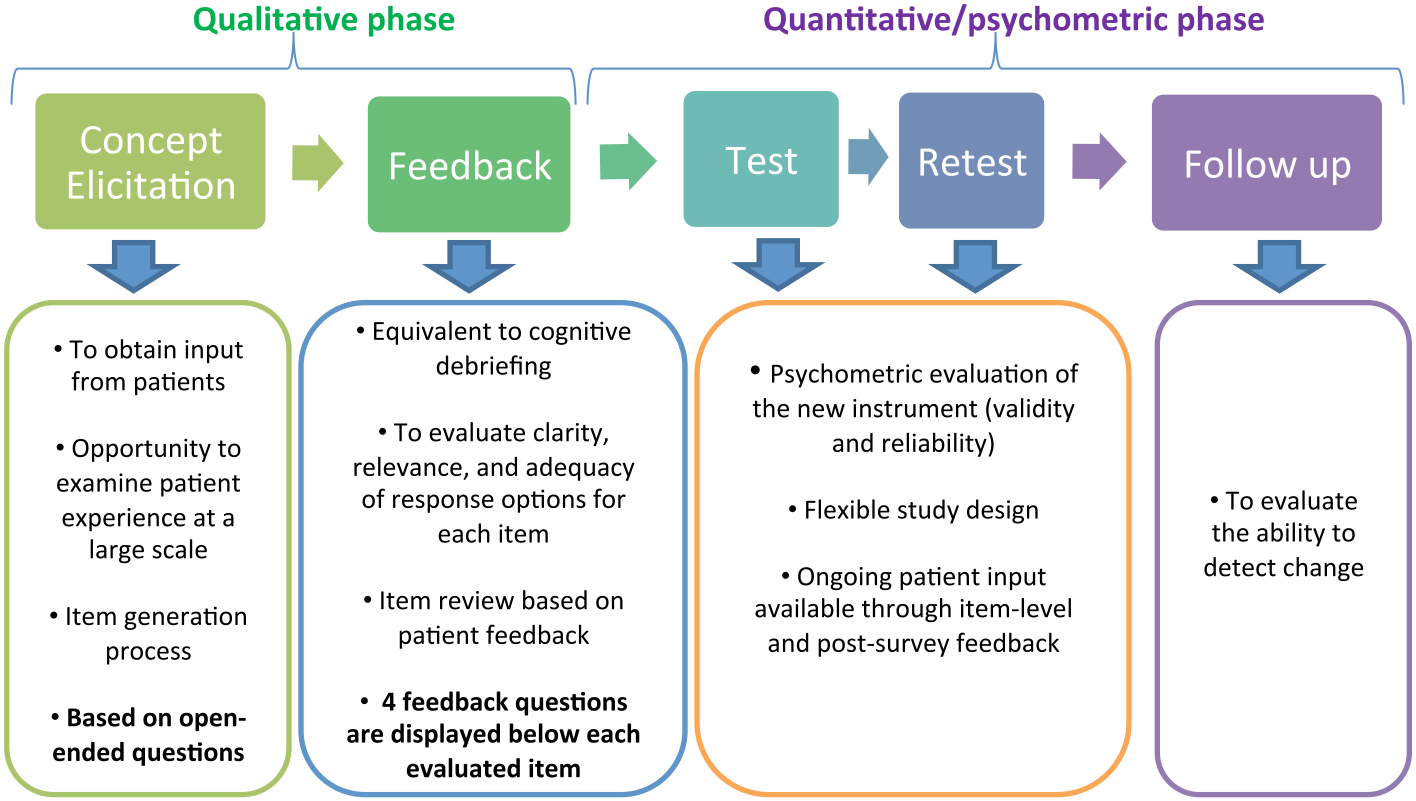
Open Research Exchange (RWJF)



Qualitative phase

Quantitative/psychometric phase

Concept Elicitation

- To obtain input from patients
- Opportunity to examine patient experience at a large scale
- Item generation process
- **Based on open-ended questions**

Feedback

- Equivalent to cognitive debriefing
- To evaluate clarity, relevance, and adequacy of response options for each item
- Item review based on patient feedback
- **4 feedback questions are displayed below each evaluated item**

Test

Retest

- Psychometric evaluation of the new instrument (validity and reliability)
- Flexible study design
- Ongoing patient input available through item-level and post-survey feedback

Follow up

- To evaluate the ability to detect change

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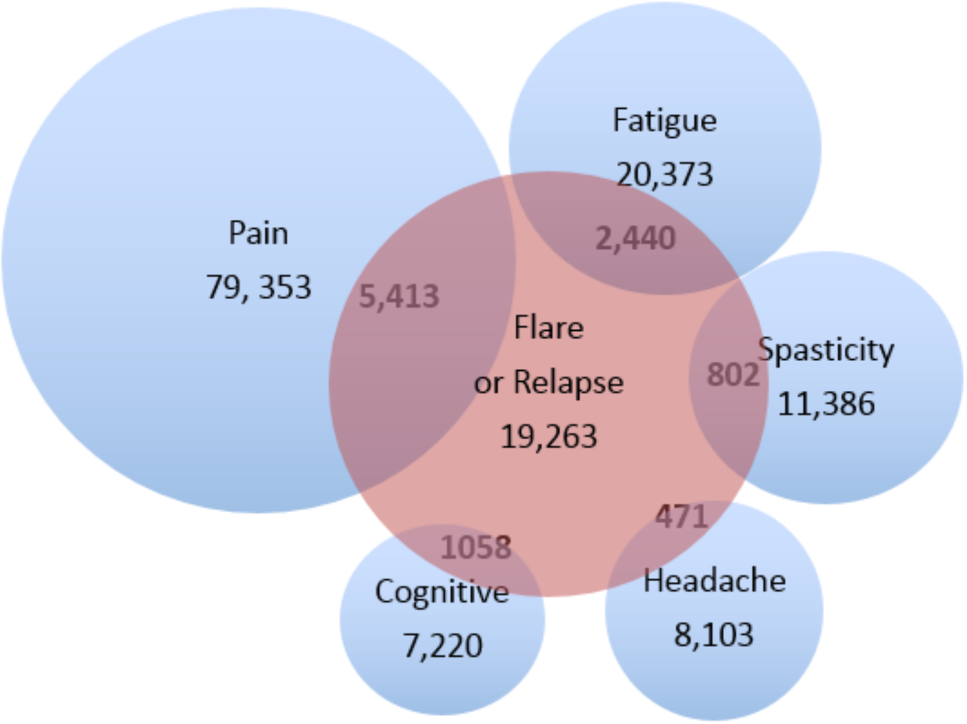
Free Text Analysis

Database case study: MS symptom analyses

% mentioned with flare

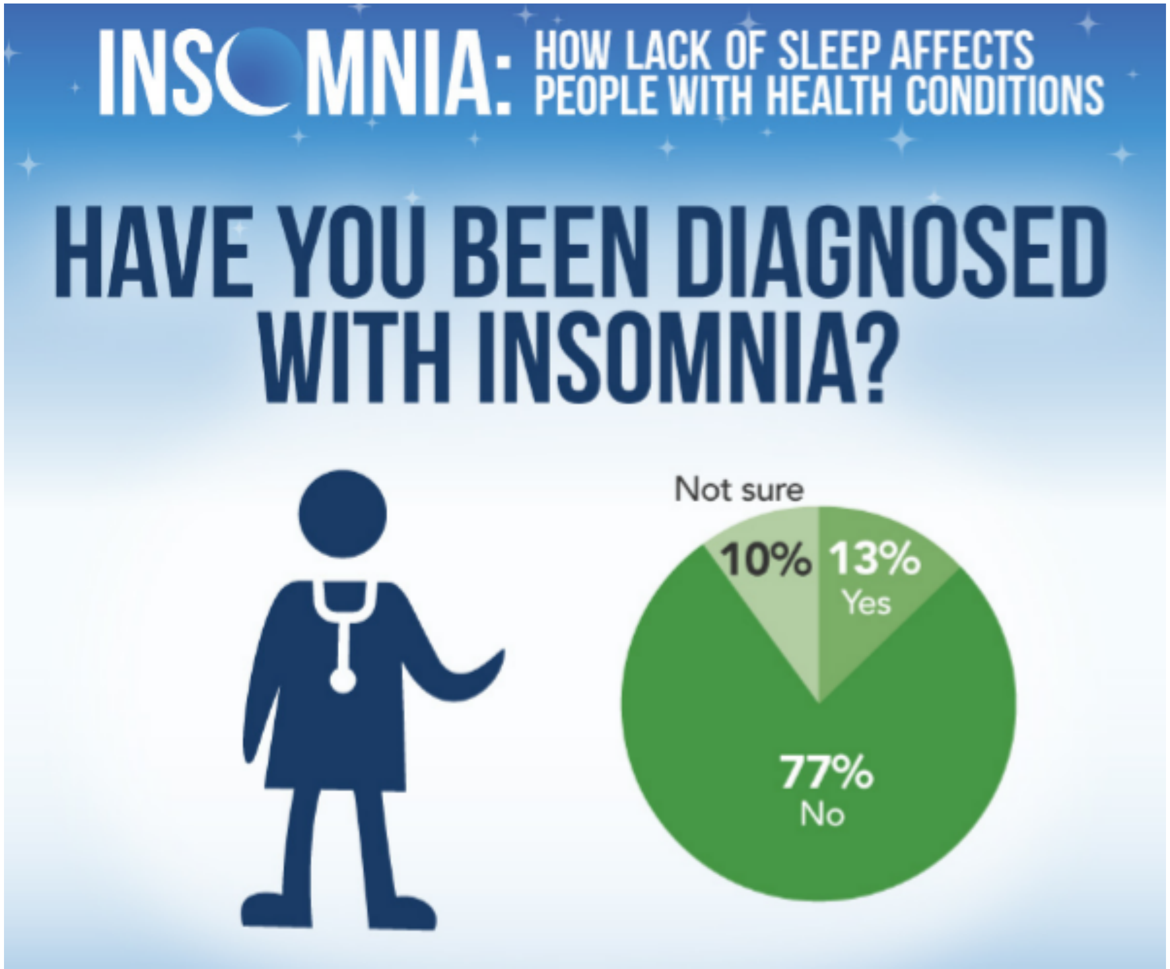
Cognitive	15%
Fatigue	11%
Concentration	11%
Spasticity	9%
Insomnia	8%
Pain	7%
Memory	7%
Headache	6%
Brain fog	6%
Attention	5%


Fatigue
20,373
Pain
79, 353
2,440
5,413
Flare
or Relapse
19,263
802
Spasticity
11,386
471
1058
Cognitive
7,220
Headache
8,103

When patients talk about relapse and flare, 28% of their discussions also broach the topic of pain, compared to 4% of conversations with also include spasticity.

Note: diagram not to scale. Non-overlap between blue circles is not indicative of no overlapping mentions.
Source: PatientsLikeMe forum data: posts, bios, event comments, and story events.

Givebacks



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PLM Publications

Journal of NEUROLOGY, NEUROSURGERY & PSYCHIATRY

JMIR

Journal of Communication in Healthcare

Clinical Orthopaedics and Related Research®

PLOS | ONE

HealthAffairs Blog

AMYOTROPHIC LATERAL SCLEROSIS
A Patient Care Guide for Clinicians

Clinical Chemistry

nature biotechnology

Movement Disorders

EUROPEAN JOURNAL OF NEUROLOGY
THE OFFICIAL JOURNAL OF THE EUROPEAN FEDERATION OF NEUROLOGICAL SOCIETIES

INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES

Neurology®

BRITISH JOURNAL OF NEUROSCIENCE NURSING

AMIA
INFORMATICS PROFESSIONALS. LEADING THE WAY.
AMIA Annual Symposium Proceedings

Epilepsy & Behavior

HEALTH AND QUALITY OF LIFE OUTCOMES

CHRONIC RESPIRATORY DISEASE

CLINICAL INVESTIGATION

Amyotrophic Lateral Sclerosis

Quality of Life Research

Acta Psychiatrica Scandinavica

BMC Medicine

Full bibliography with links to articles:
https://www.patientslikeme.com/research/publications

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Emil Chiauzzi, Ph.D.
Research Director
echiauzzi@patientslikeme.com

Appendix

PatientsLikeMe Values

Honor Patients’ Trust

Our patients trust us with their most valued health information. We honor that trust, and we are dedicated to advancing the knowledge in the disease with the information they share.

Openness

Per our Openness Philosophy, we believe that sharing health information is good. Why? Because sharing will drive massive change in healthcare.

PATIENTS FIRST

No surprises. Our members shouldn't be surprised by anything we do. Our goal is to disclose what we do with members' information, how we make money, as well as all of our partnerships on the site.

Transparency

When people see our site, we want them to think, “Wow!” Achieving our vision takes flawless execution and a deep understanding of patient needs.

Create WOW!

Privacy Policy

No guarantees on privacy

Shared and restricted data

Transparency about the use of data

Members may choose to opt out

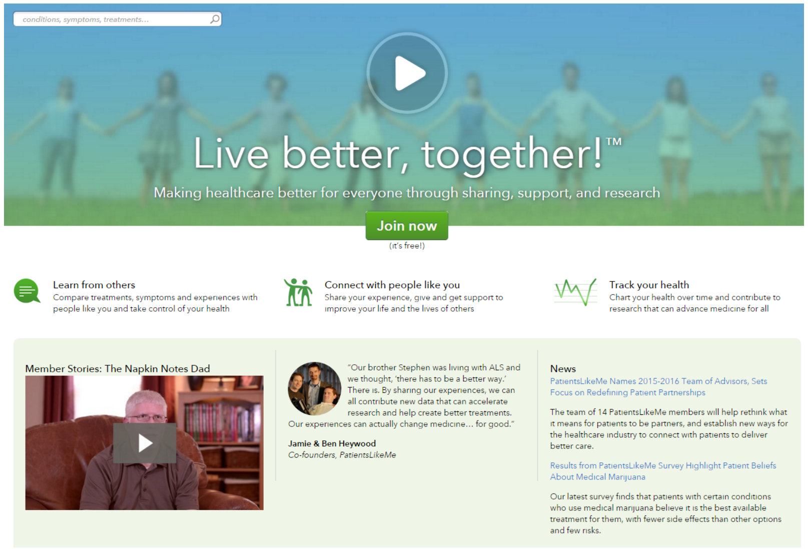
Certain studies may require IRB/informed consent

Data sharing agreements

Qualitative data challenges

Seek permission to use member profiles in published material

Consenting and Sharing Information



Live better, together!™

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

(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: The Napkin Notes Dad

"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

PatientsLikeMe Names 2015-2016 Team of Advisors, Sets Focus on Redefining Patient Partnerships

The team of 14 PatientsLikeMe members will help rethink what it means for patients to be partners, and establish new ways for the healthcare industry to connect with patients to deliver better care.

Results from PatientsLikeMe Survey Highlight Patient Beliefs About Medical Marijuana

Our latest survey finds that patients with certain conditions who use medical marijuana believe it is the best available treatment for them, with fewer side effects than other options and few risks.

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