

patientslikeme®



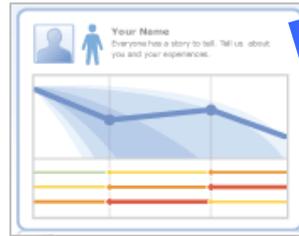
Chronic Fatigue Syndrome Advisory Committee:
Patient Registry Model

Ben Heywood, Co-founder & President

June 17, 2014

PatientsLikeMe: share, connect, learn

Step 1:
Create/update your patient profile and share it with others



Step 2:
Find support from and compare experiences with other patients like you



patientslikeme®
patient engagement cycle

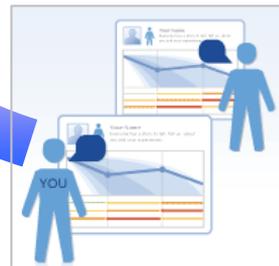


Step 5:
Play an integral and participatory role in your health care

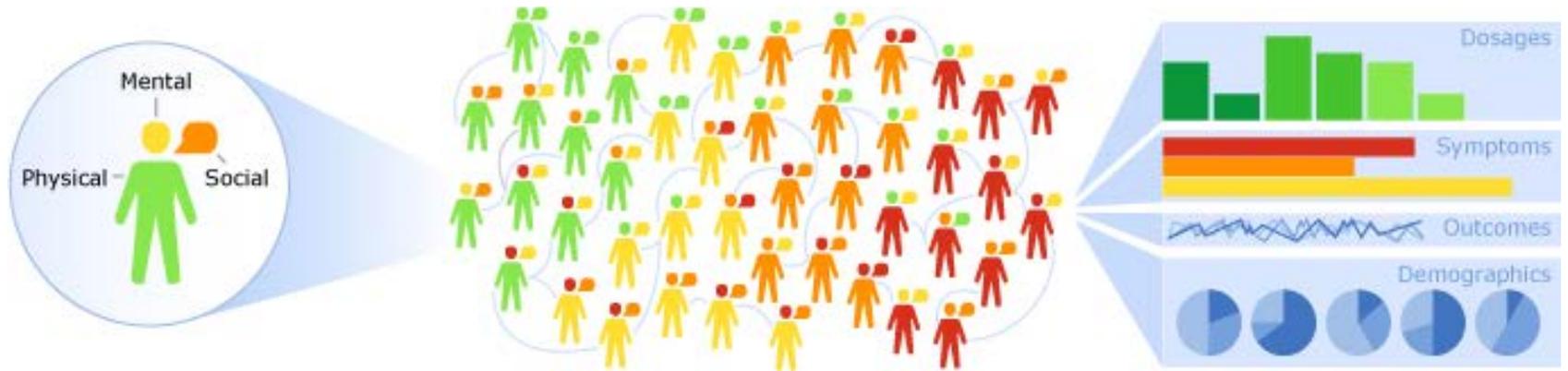
Step 3:
Learn from aggregated community Treatment and Symptom Reports



Step 4:
Take your patient profile to your provider appointments for an improved dialogue



Patient Powered Research Network



patients

data

insights

- **260,000+ Patients**
- **2000+ Diseases**
- **Top Communities**

Fibromyalgia
Multiple Sclerosis
Major Depressive Disorder
Diabetes Type 2
Generalized Anxiety Disorder
Chronic Fatigue Syndrome
Epilepsy
Parkinson's Disease
Rheumatoid Arthritis

- **21 mm structured data points**

400,000 symptom reports
350,000 condition PRO scores
150,000 side effect reports
110,000 treatment stop reports
100,000 quality of life scores

- **3 mm free text fields**

2 mm forum conversations
750,000 journal stories
320,000 private messages
90,000 peer-peer comments

- **40+ peer-reviewed papers**

Networking 'dose effect'
Off-label effectiveness data
Data sharing preferences
Burden of chronic illness
Risk / benefit tolerance
Insomnia study
Patient perspective on trials

- **Safety monitoring platform**
- **Patient-generated taxonomy**

Patient-centered persona based design



Tweaker/tracker

Help me capture the data that I care about



Leader/connector

Help me organize groups of people with common goals



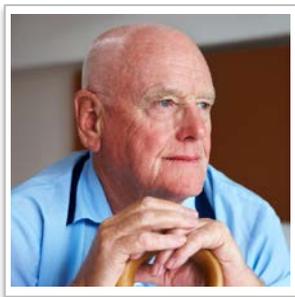
Activated, fact-based

Help my providers know me and use my data to improve my care



Slow decision possible

Help me manage today's symptoms without worrying about tomorrow's



Contented

Help me focus on my grandchildren, not my health



Fast decision required

Help me make the right choice about treatment...fast



In limbo

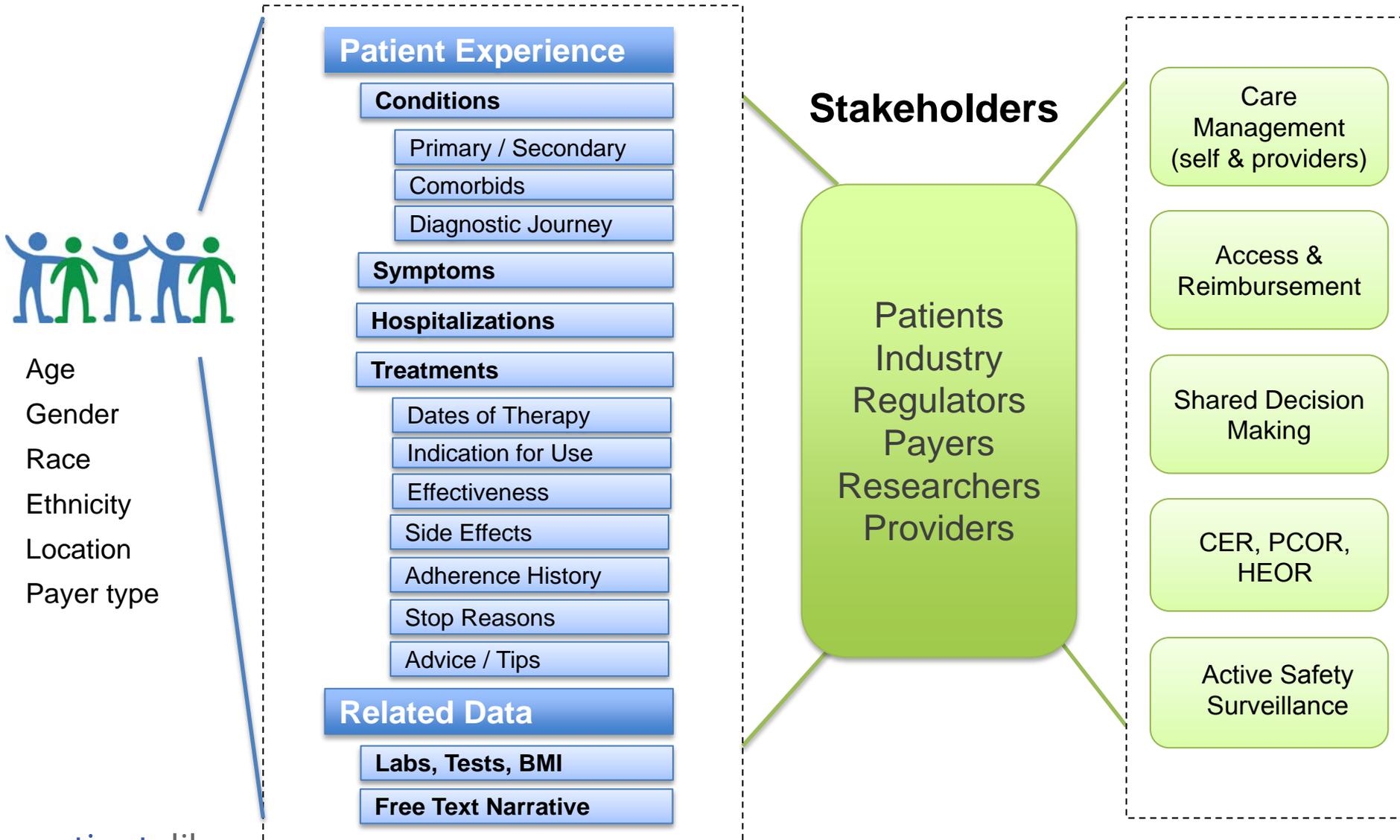
Help me figure out what's wrong with me



Caregiver

Help me give both of my boys a good life

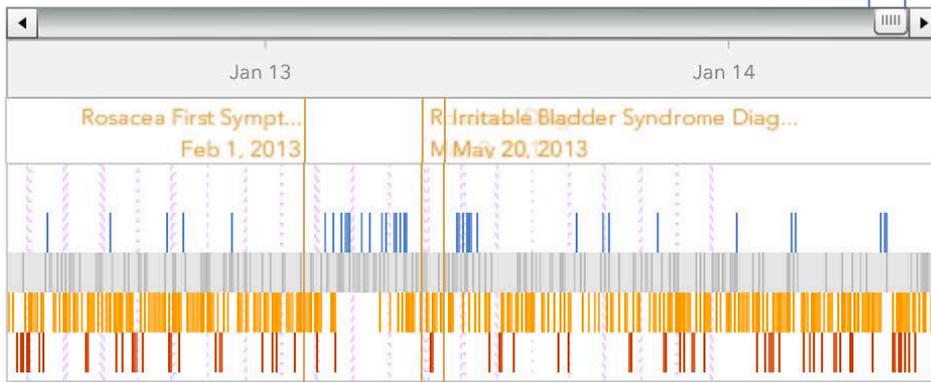
Patient-generated health data: common standards



ME/CFS Patient Experience



CFS:5y Dx
FM:5y Dx
F49y

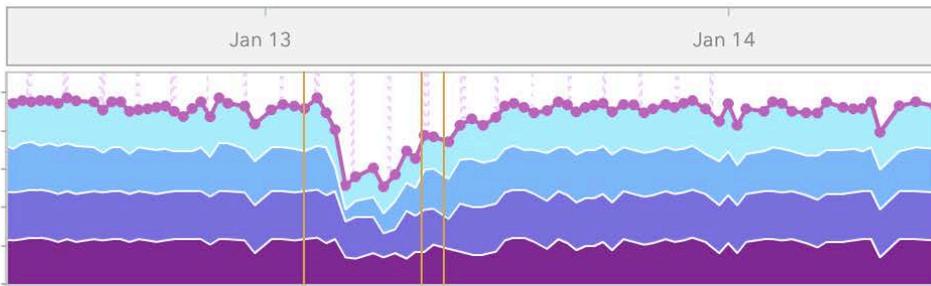


Neutral

Jun 11, 2014 2:44 PM

Not bad overall, but pain pills are a necessity today. I woke up in a lot of ...

[More](#)

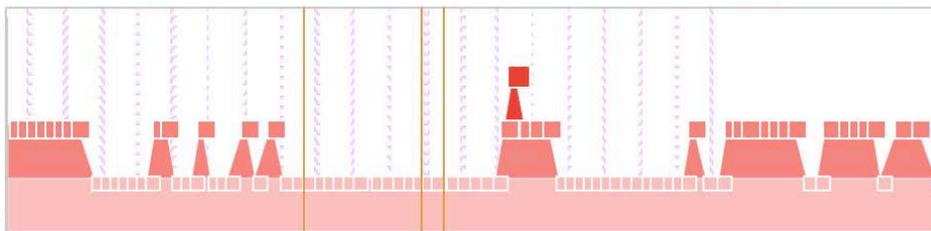
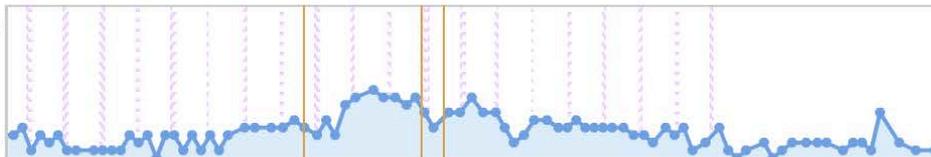


46

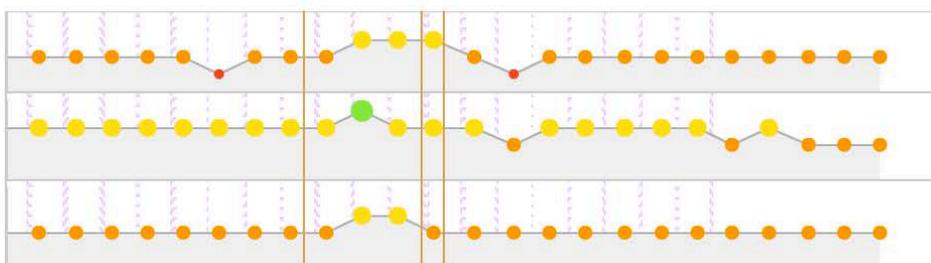
Last score

Last update:

Jun 9, 2014



■ PFRS External Stress

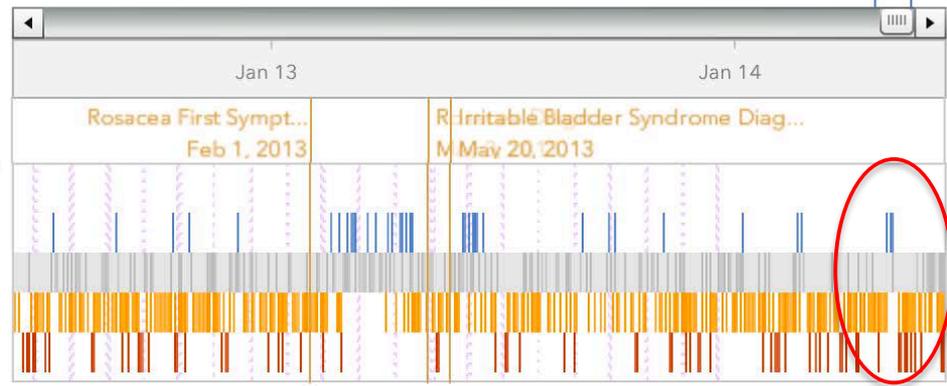


Social: Bad ●

Last update:
Apr 27, 2014

Mental: Bad ●

Physical: Bad ●



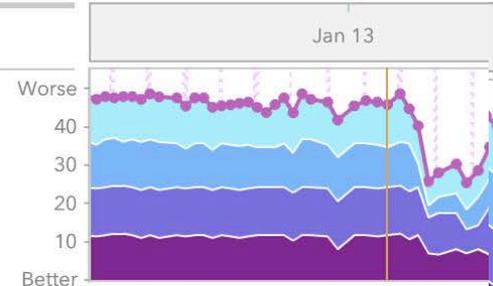
Neutral
 Jun 11, 2014 2:44 PM
Not bad overall, but pain pills are a necessity today. I woke up in a lot of ...
[More](#)

▼ **InstantMe**

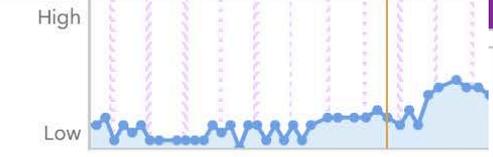
- Very Good
- Good
- Neutral
- Bad
- Very Bad

▼ **PFRS**

- ▼ PFRS
- Fatigue
 - Sleep disturbances
 - Morning stiffness
 - Pain

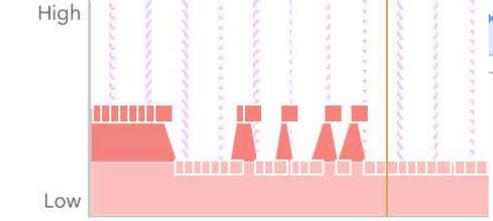


▼ **PFRS Function**



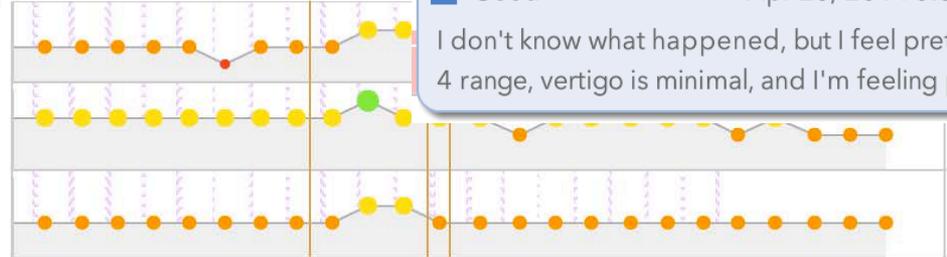
▼ **PFRS External Stress**

- Overwhelming
- Severe
- Moderate
- Low
- None



▼ **Quality of Life**

- Best
- Good
- Bad
- Worst



InstantMe ✕

May 4, 2014 8:02 PM - Apr 26, 2014 3:52 PM

Very Bad May 4, 2014 8:02 PM
 Oh boy, that trip really did me in. I hurt so much.

Neutral May 1, 2014 10:12 AM
 Achy muscles and a really sore knee for some reason. I'm hoping a shower will help.

Good Apr 30, 2014 12:18 PM
 Muscles are still sore from overdoing it, but other than that I feel pretty good. I probably should have stretched before doing stuff, it's been so long since I was able to do anything but sit in a chair all of my muscles are out of shape!

Good Apr 29, 2014 9:28 AM
 A bit sore and achy, but I'm feeling pretty good otherwise.

Good Apr 26, 2014 3:52 PM
 I don't know what happened, but I feel pretty decent! Pain levels are in the 3-4 range, vertigo is minimal, and I'm feeling pretty upbeat. What a nice change!

Mental: Bad Apr 27, 2014

Physical: Bad

CFS:5y Dx
FM:5y Dx
F49y

▼ Treatments

Side Effect

Evaluation

Roll over bars for more information

Jan 13	Jan 14	
		▼ Fibromyalgia
		Flexeril
		Hydrocodone-Acetaminophe
		Lyrica
		Trazodone
		Tramadol
		Naproxen OTC
		Topiramate
		Citalopram
		Gabapentin
		Cymbalta
		Savella
		▼ Amblyopia
		Glasses / contacts
		▼ Hypothyroidism
		Levothyroxine
		▼ Myalgic Encephalomyelitis/Chronic Fatig
		Lyrica
		Citalopram
		Cymbalta
		▼ Seasonal Allergy
		Fexofenadine
		Cetirizine
		Loratadine
		▼ Acid reflux
		Omeprazole OTC



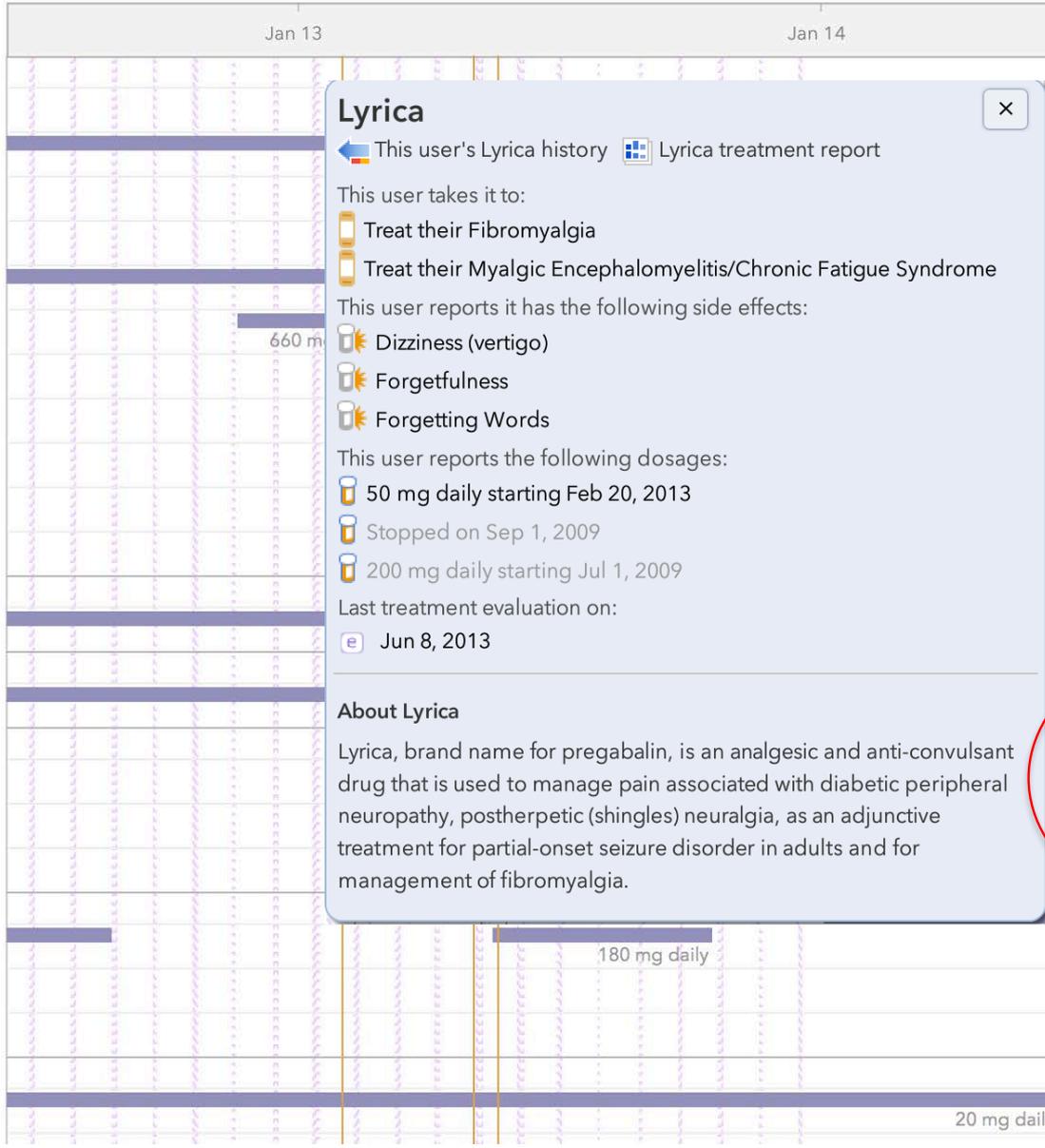
CFS:5y Dx
FM:5y Dx
 F49y

▼ **Treatments**

 Side Effect

 Evaluation

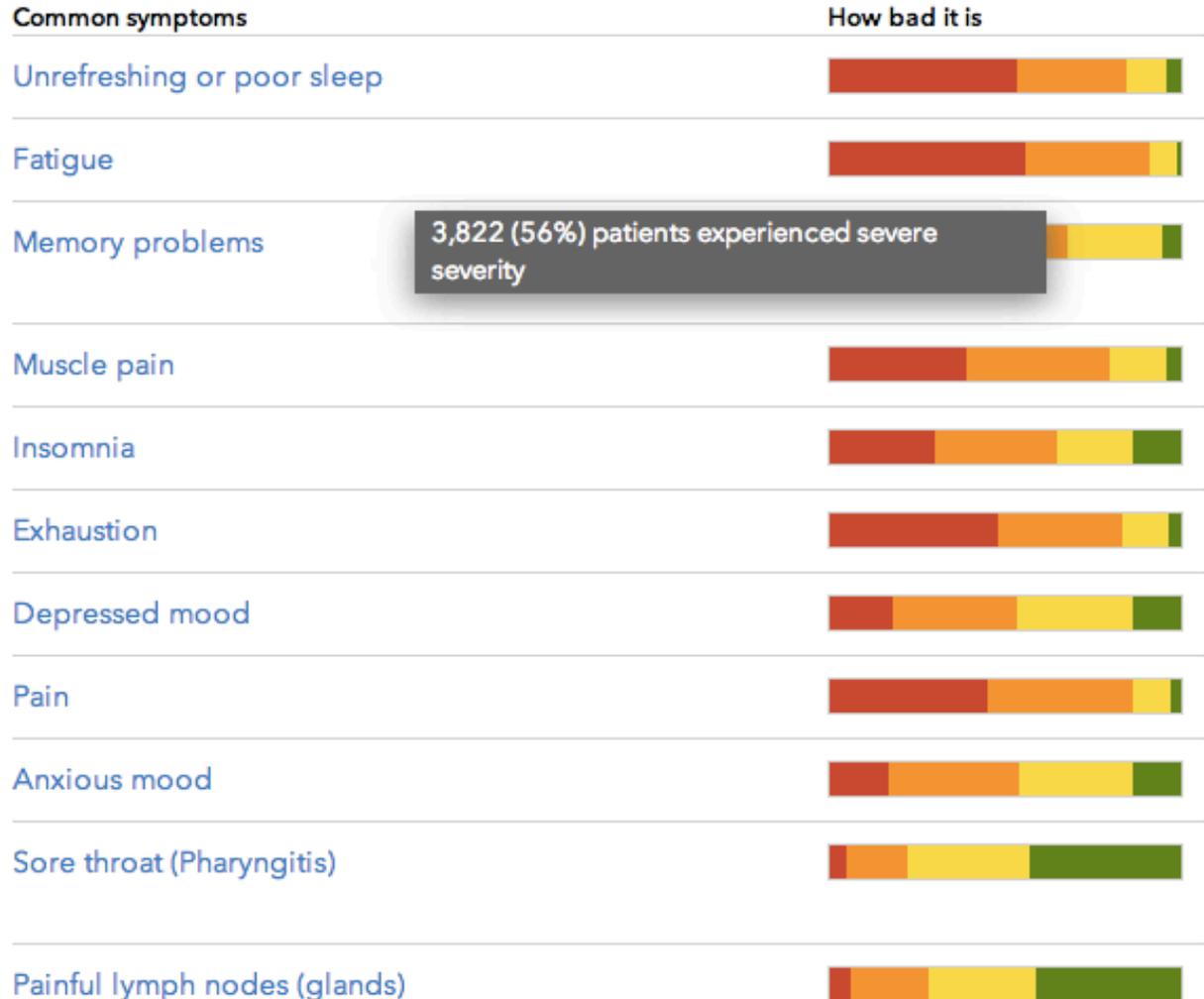
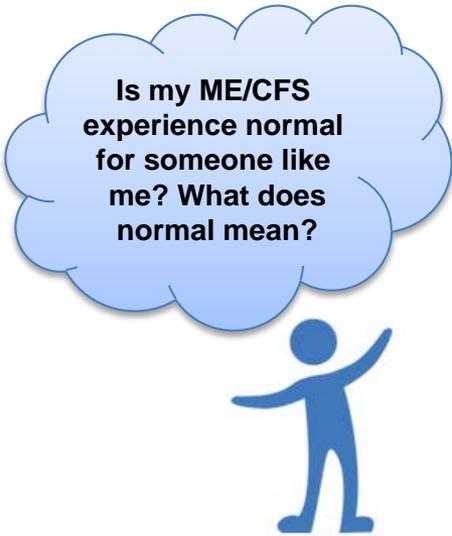
 Roll over bars for more information



- ▼ **Fibromyalgia**
 -   Flexeril
 -   Hydrocodone-Acetaminophe
 -   Lyrica
 - Trazodone
 -   Tramadol
 -   Naproxen OTC
 -   Topiramate
 -   Citalopram
 -  Gabapentin
 -  Cymbalta
 -   Savella
- ▼ **Amblyopia**
 - Glasses / contacts
- ▼ **Hypothyroidism**
 -  Levothyroxine
- ▼ **Myalgic Encephalomyelitis/Chronic Fatig**
 -   Lyrica
 -   Citalopram
 -  Cymbalta
- ▼ **Seasonal Allergy**
 -  Fexofenadine
 -   Cetirizine
 - Loratadine
- ▼ **Acid reflux**
 -  Omeprazole OTC

Patient-centered community reports

What is it like to have ME / CFS?



Patient-centered community reports

What do patients use to manage ME / CFS?

Treatments reported by members	Perceived effectiveness	Overall rating of side effects	# of Evaluations
Pregabalin (Lyrica)			121
Duloxetine (Yentreve, Cymgen, Yelate, Cymbalta)			103
Naltrexone (ReVia, Low Dose Naltrexone (LDN))			18
Amphetamine-Dextroamphetamine (Adderall, D-Amphetamine Salt Combo, Amphetamine-dextroamphetamine ER, Amphetamine Salts)			14
Rest			10
Gabapentin (APO-Gabapentin, Gralise, PMS-Gabapentin, Horizant)			6
Tramadol (Durella, Tradorec XL, Tramadol ER, Ralivia)			5
CoQ10 (CoEnzyme Q10) (CoQmax, Bio Organics CoQ10 Capules, Trader Joe's Co Enzyme Q10, Whole Foods CoQ10 Chewable Tablets)			5
Armodafinil (Nuvigil)			5

How do other patients like me treat their ME / CFS? What were their results and experiences?



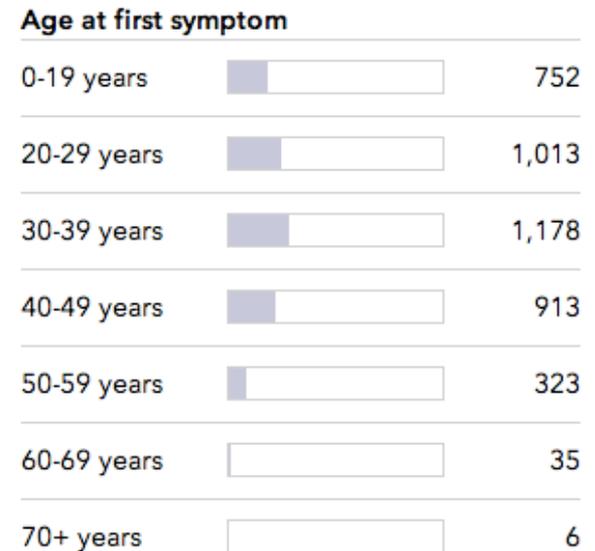
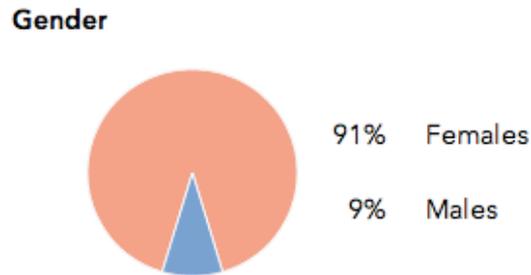
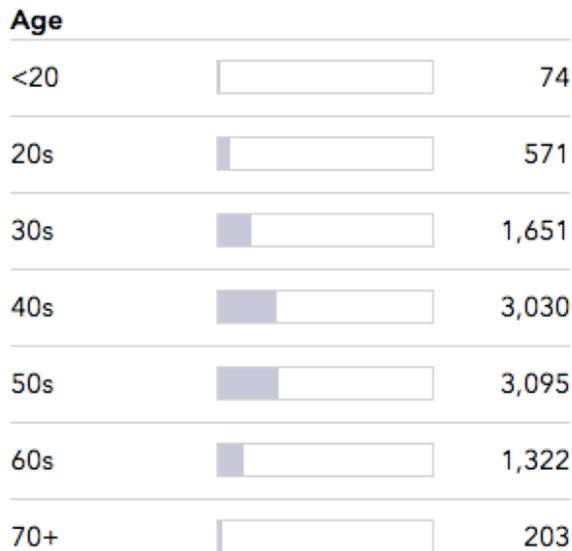
Current ME/CFS Registry Demographic Data

Who has Myalgic Encephalomyelitis/Chronic Fatigue Syndrome on PatientsLikeMe?

11,015 patients have this condition

72 new patients joined this month

2,687 say ME/CFS is their primary condition



Patient Reported Outcomes

Condition-specific Outcome Measures

Measure	Condition
Multiple Sclerosis Rating Scale (MSRS)	Multiple Sclerosis
Pulmonary Fibrosis Severity Score	Pulmonary Fibrosis
Pain and Fatigue Rating Scale (PFRS)	Fibromyalgia Chronic Fatigue Syndrome
Seizure Survey	Epilepsy
Functional Rating Scale	Amyotrophic lateral sclerosis
Parkinson's Disease Rating Scale (PDRS)	Parkinson's Disease
Psoriasis	Dermatology Quality of Life Index
Movement Disorder Rating Scale	Multiple System Atrophy Progressive Supranuclear Palsy
Autism Treatment Evaluation Checklist (ATEC)	Autism Spectrum Disorder
Neuromyelitis Optica Rating Scale (NORS)	Neuromyelitis Optica



faq

advisors

pilot researchers

for patients

about us

researcher login



design

Leverage new, specialized tools to quickly design and field measures.



test

Access a network of real patients to rapidly test new measures and get feedback on your instrument development.



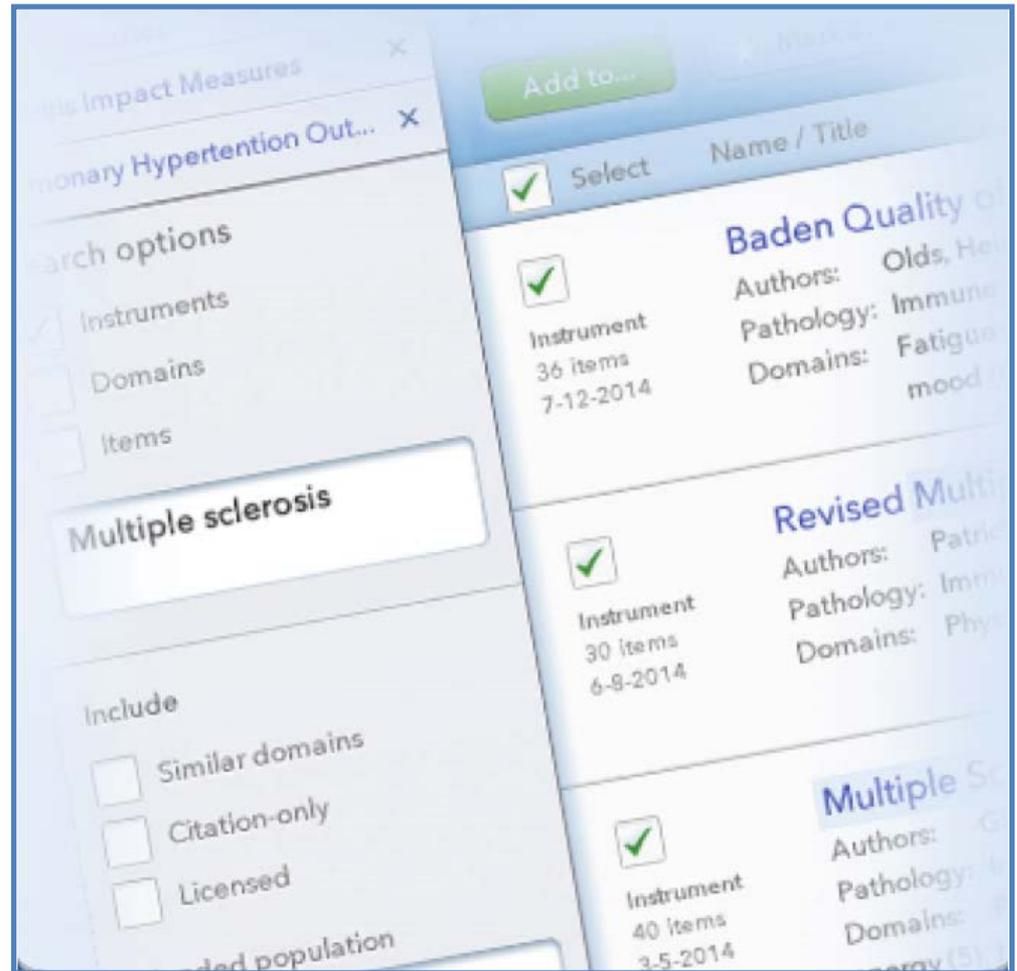
share

Be among the first to browse and contribute to the world's only open library of patient-reported instruments and health measurements.



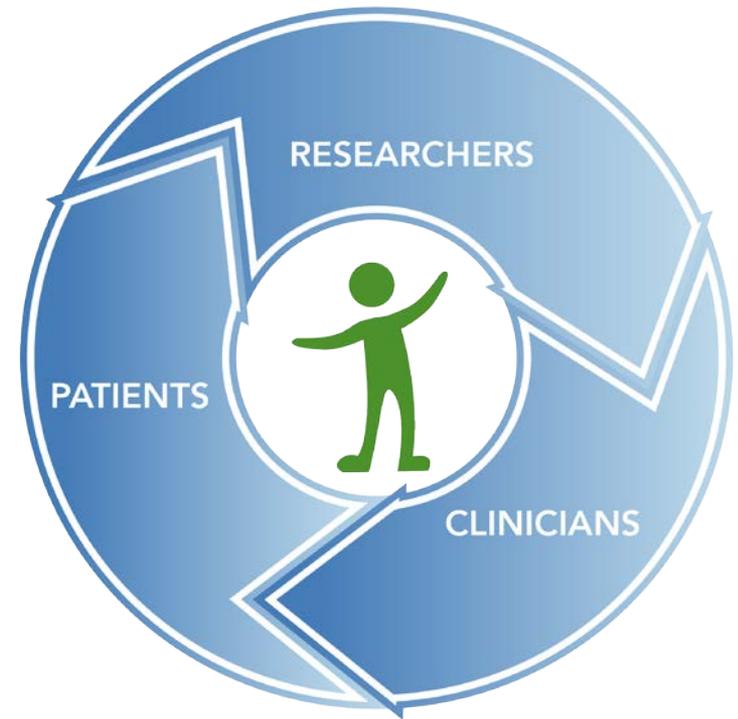
How Open Research Exchange works

- Quickly design and field measures
- Test and get feedback from real patients on our network
- Add to and browse the only open library of patient-reported instruments and health measurements



PRO measure development platform

- ✓ **Clear** – I understand what it means
- ✓ **Answerable** – it's information I have
- ✓ **Efficient** – it respects my time
- ✓ **Relevant** – describes my experience
- ✓ **Educational** – what is & isn't part of my condition
- ✓ **Harmless** – doesn't make me sad, anxious, symptomatic
- ✓ **Actionable** – helps me change, discuss with providers



Research

Sharing health data => Shared insights

JOURNAL OF MEDICAL INTERNET RESEARCH

Wicks et al

Original Paper

Sharing Health Data for Better Outcomes on PatientsLikeMe

Paul Wicks, PhD; Michael Massagli, PhD; Jeana Frost, PhD; Catherine Brownstein, PhD; Sally Okun, RN; Timothy Vaughan, PhD; Richard Bradley, RN; James Heywood, SB
PatientsLikeMe Inc., Research & Development, Cambridge, United States

Corresponding Author:

Paul Wicks, PhD

PatientsLikeMe Inc.

Research & Development

155 Third Street, Suite 0234

European Journal of Neurology 2008

doi:10.1111/j.1468-1331.2008.02107.x

ALS patients request more information about cognitive symptoms

P. Wicks and J. Frost

PatientsLikeMe Inc., Cambridge, MA, USA

Keywords:

ALS, decision making, ethics, emotional lability, frontotemporal dementia.

Background and purpose: Once thought to impact only voluntary motor function, ALS/Motor neuron disease (MND) is now seen as a multi-system disorder in which a minority of patients experience mild cognitive dysfunction or frontotemporal dementia. Despite clinical guidelines advocating supplying complete information to

JOURNAL OF MEDICAL INTERNET RESEARCH

Frost & Massagli

Original Paper

Social Uses of Personal Health Information Within PatientsLikeMe, an Online Patient Community: What Can Happen When Patients Have Access to One Another's Data

Jeana H Frost, PhD; Michael P Massagli, PhD

PatientsLikeMe Inc, Cambridge, MA, USA

Corresponding Author:

Jeana H Frost, PhD

PatientsLikeMe Inc

222 Third Street, Suite 0234

After using PatientsLikeMe...

- 71% HIV patients agreed or strongly agreed that they took more of an interest in their lab values
- 63% of members agreed they had a better understanding of the consequences of taking a “drug holiday”
- 12% of members changed their physician

Patient illuminate gaps in standard of care

Table 1 Patient assessment of quality measure performance

	Strongly agree	Agree	Disagree	Strongly disagree	NA
1a. I am confident I know the name of the seizures that I experience	51%	38%	8%	4%	0%
1b. At each visit, my epilepsy doctor asks me how many seizures I have had since the last visit for each type of seizure I experience	62%	25%	5%	5%	2%
2. I am confident I know the name of the type of epilepsy or seizure syndrome that I have	48%	33%	13%	6%	0.5%
3. I have had (or been offered) an EEG (electroencephalogram) at least once	89%	10.5%	0%	0.5%	0%
4. I have had (or been offered) a brain scan at least once (e.g. MRI, CT, or CAT scan)	86%	11%	1%	2%	0.5%
5. The doctor who treats my seizures asks me about the side effects of my medication at every visit	44%	24%	15%	14%	2%
6. I have been referred to an epilepsy specialist to discuss treatments that are not drugs, such as surgery or vagal nerve stimulation (VNS), at least once in the past 3 years; or if I am already followed by an epilepsy specialist then we have discussed these therapies; or, I have already had surgery or VNS for my epilepsy	35%	13%	14%	20%	19%
				53%	
7. I have discussed safety issues with the physician that treats my seizures at least once in the past year (e.g., driving, bathing, injury prevention)	48%	26%	9%	12%	5%
8. I have spoken with the physician that manages my seizures about how my antiepileptic medications might reduce the effectiveness of any contraception/birth control I am using or plan to use in the future	27%	19%	10%	7%	37%
				54%	

Wicks & Fountain (2012) Patient assessment of physician performance of epilepsy quality of care measures. *Neurology Clinical Practice* 2:335

Excerpt: The Health Blog

HealthAffairs Blog

The Patient Engagement Pill: Lessons From Epilepsy

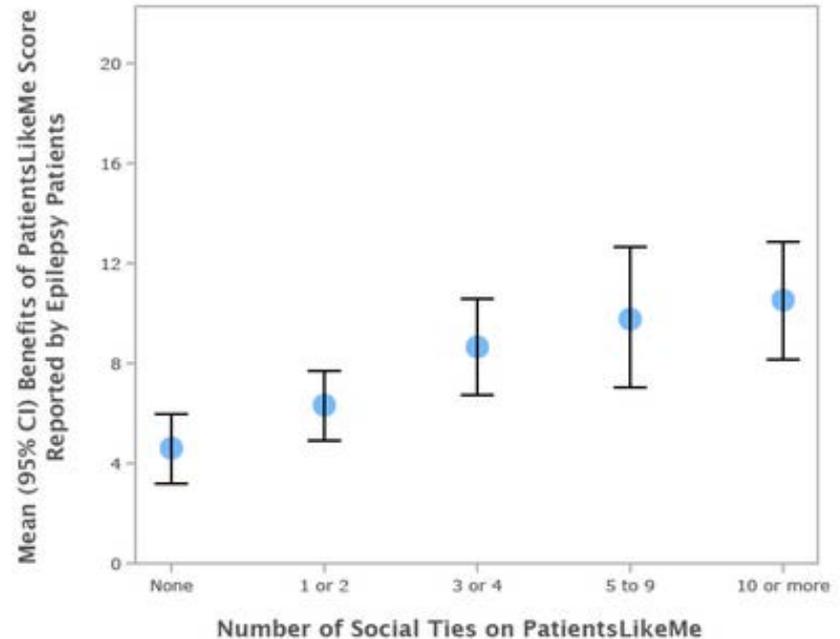
February 7th, 2013



by **Paul Wicks** and **John Hixson**

“If patient engagement were a drug, it would be the blockbuster drug of the century and malpractice not to use it.”

- Leonard Kish 8/28/12
HL7 Standards Blog



Accelerated clinical discovery using self-reported patient data collected online and a patient-matching algorithm

Paul Wicks, Timothy E Vaughan, Michael D M



THE WALL STREET JOURNAL
WSJ.com

ALS Study Shows Promise of Social

HEALTH INDUSTRY | APRIL 24, 2011, 5:12 P.M. ET

By **AMY DOCKSER MARCUS**

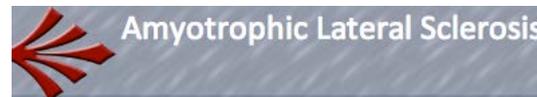
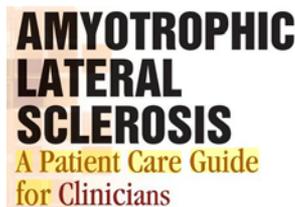
3. A new clinical trial found that lithium doesn't slow the devastating progression of Lou Gehrig's disease
4. The study was based on data contributed by 596 patients with the disease, known formally as amyotrophic lateral sclerosis, pioneering use of a social network to enroll patients and report and collect data may deliver dividends
5. The new study, published online in the journal Nature Biotechnology, represents an early example of how social networking could play a role in medical trials, an area of medical science with strict procedures that consider especially difficult to apply in the

Control	Control number,5
Sex,M	Sex,M
Days since onset,2307	Days since onset,2307
Onset symptom,Arms	Onset symptom,Arms
Days since "treatment start" (time zero),	Days since "treatment start" (time zero),
Days since birth,13804	Days since birth,13804
Days since death,NaN	Days since death,NaN
Days since FRS score date,FRS scores	Days since FRS score date,FRS scores
2307,48	2307,48
2976,48	2215,48
4743,48	1549,17
4498,48	1532,11
2328,48	4378,48
2022,48	4813,48
3647,36	1500,18
3433,30	1414,10
3068,17	1327,8
2929,15	1309,8
2642,10	1056,8
2307,1	2973,44
1938,1	2882,44
	2784,44
	1184,8
	1312,36



PatientsLikeMe publications

40+ disease specific and general scientific research publications



Acta Psychiatrica Scandinavica

Quality of Life Research

patientslikeme®

Partner Opportunities

A turnkey registry for research, recruitment

Traditional Clinical Research



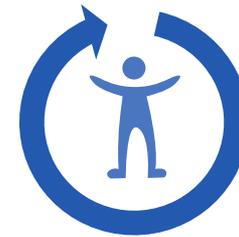
- A well-defined population studied under controlled conditions
- Patients are subjects, not partners in the research since research is designed to test against a specific question or clinical insight

Traditional Patient Registry



- A well-defined, growing population fitting inclusion and exclusion criteria
- Patients only interact with researchers during the study

PatientLikeMe's Open Registry



- Comprehensive patient population where researchers can integrate new questions and measures anytime
- Patients are proactively involved in research and can interact regularly with researchers
- Offers 360 degree view of patients, 365 days a year

Partnering with PatientsLikeMe



Live better, together!™

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



Reach



Increased awareness...

- Customized landing pages
- Customized nonprofit page in the community to target awareness campaigns to your followers
- Managed interactions and communications with patients, advocates and mentors
- Promote programs using profile feeds and auto following
- Guest partner hosting on forum
- Cross promotions via Facebook, Twitter and Flickr
- Joint press releases, blogs



Useful resources & links

[Chronological Bibliography June 2014 PDF](#)

At PatientsLikeMe, every experience counts – toward a better life for patients living with disease and a better future in healthcare.

[Data For Good video](#)



The PatientsLikeMe Story

Inspired by the life experiences of Stephen Heywood, PatientsLikeMe was founded in 2004 by his brothers Jamie and Ben and long-time friend Jeff Cole. Stephen was diagnosed at the age of 29 with amyotrophic lateral sclerosis (ALS). [Read more](#)



[A family's story](#)