A Poster Bibliography of PatientsLikeMe
The complete collection of PatientsLikeMe research posters as of September 2014
2014
The POEM Study: Testing the Impact of a Digital Health Platform in U.S. Veterans with Epilepsy
Presented: American Academy of Neurology (AAN) 2014
Primary Community: Epilepsy

In collaboration with UCSF and the VA, PatientsLikeMe conducted a study to assess the effectiveness of our online platform as an intervention to increase the self-management and self-efficacy of veterans living with seizures. A group of 92 participants completed validated self-report measures at both baseline and 6-week follow-up and showed significant improvement on both outcomes. This pragmatic study demonstrates the potential impact of digital health solutions in epilepsy.


Patient-Centered Outcomes in Diabetes Care: A Study of A1C Awareness and Diabetes Distress
Presented: American Diabetes Association (ADA) 2014
Primary Community: Diabetes

In this study, more than 550 patients with diabetes were surveyed about their level of diabetes control as measured by their most recently reported hba1c and the patient reported outcome measure, the Diabetes Distress Scale (DDS). Items causing significant distress, such as “ending up with long-term complications, no matter what I do,” “feeling that I am not sticking closely enough to a good meal plan,” or “feeling that I am often failing with my diabetes regimen” were correlated with the perception that their A1C numbers meant they were doing poorly ($r = 0.4 - 0.5$). Many people interpreted their A1C as being worse than it actually was and might benefit from extra support and education.

• Katic BJ, Jackson RA (2014) Patient-Centered Outcomes in Diabetes Care: A Study of A1C Awareness and Diabetes Distress, Diabetes, 63(S1):A174
• **Patient-Informed Clinical Trials: Cross-Sectional Survey on a Patient Powered Research Network, PatientsLikeMe**

Presented: Drug Information Association (DIA) 2014  
Primary Community: General

This study explores the motives, barriers, and opportunities to enhance clinical trial recruitment for patients with chronic disease through a patient powered research network (PPRNs). The results from a cross-sectional survey of members on PatientsLikeMe.com indicated that PPRNs appear to be particularly enriched for patients who have either been in clinical trials or who have a high degree of interest in taking part in them. PatientsLikeMe allows patients to be made aware of trials for which they might be eligible, gain their feedback on the decision-making process they go through when deciding to enroll, and once enrolled receive ongoing feedback about their experiences of being a participant to help trial sponsors and researchers to optimize their clinical operations.


• **Characteristics of an Online, Patient-powered Research Network of Idiopathic Pulmonary Fibrosis Patients**

Primary Community: Idiopathic Pulmonary Fibrosis (IPF)

This poster aims to describe the demographic and clinical characteristics of the idiopathic pulmonary fibrosis (IPF) community at PatientsLikeMe.com. The PatientsLikeMe patient registry contains 2,106 patients with pulmonary fibrosis, of which 2,041 identified with having IPF, at the time of publication. The mean age of the IPF population was 65 years; 50% of the community were male; 71% of the patients reported taking a treatment for their IPF; 2.1% have received a lung transplant and 4.4% are currently being evaluated or registered to receive a transplant.

• **An Open Research Exchange for Online Patient Feedback in PRO Development**
  
  Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR) 2014  
  Primary Community: General  
  Sponsor: Robert Wood Johnson Foundation  
  
  The Open Research Exchange (ORE) software platform was built by PatientsLikeMe to facilitate the development of patient-reported outcome (PRO) instruments. This poster walks through the steps of developing and evaluating the ORE platform. It was found that the platform enables rapid and effective patient engagement in the PRO development process at a large scale. Additionally, the anonymous web form creates a more comfortable environment for patients to respond to embarrassing topics, and provide honest and blunt feedback about poorly phrased or insensitive questions.  
  

• **Online Social Networks-Based Qualitative Research to Identify Patient-Relevant Concepts in Chronic Lymphocytic Leukemia**
  
  Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR) 2014  
  Primary Community: General  
  Sponsor: Janssen  
  
  The aim of this study was to engage members of the PatientsLikeMe community diagnosed with chronic lymphocytic leukemia (CLL) to explore the feasibility and utility of using social media-based patient networks to gather qualitative concept elicitation data on the patient experience of CLL. A questionnaire was administered using the PLM platform to identify relevant disease-specific symptoms and impacts experienced by patients with CLL.  
  
2013

**Sleep Problems and Quality of Life in Patients with Idiopathic Pulmonary Fibrosis**
Presented: Pulmonary Fibrosis Summit (PFS) 2013
Primary Community: Idiopathic Pulmonary Fibrosis (IPF)

Sleep problems are increasingly common among those with idiopathic pulmonary fibrosis (IPF), and can have a profound negative impact on quality of life (QoL). A survey was sent to all PatientsLikeMe users to collect data on the degree and duration of sleeping problems and their impact on quality of life. Sleeping problems were fairly prominent in patients with IPF; more than half of all IPF patients rated the severity of their sleeping problems to be moderate, severe, or very severe. The survey also showed that sleeping problems were significantly associated with both increased IPF symptom duration and decreased quality of life.


**ORE: An Online Platform to Accelerate Patient Involvement in Open Instrument Development**
Presented: International Society for Quality of Life Research (ISOQOL) 2013
Primary Community: General
Sponsor: Robert Wood Johnson Foundation

The Open Research Exchange (ORE) is an online research platform designed to help instrument developers include the “patient voice”, receive patient feedback, and to facilitate the distribution of patient reported outcomes (PROs) to more patients. The ORE pilot began in April 2013. This poster outlines the results from the pilot, patient feedback about the surveys fielded via this platform, and discusses the benefits and advancements of ORE.

PatientsLikeMe Epilepsy Community: Factors Affecting Quality of Life
Presented: American Academy of Neurology (AAN) 2013
Primary Community: Epilepsy
Sponsor: UCB Pharma

Members of the PatientsLikeMe epilepsy community reported that memory problems, fatigue and somnolence were the most frequently occurring symptoms, along with treatment-related side effects. The differences in content of Quality of Life in Epilepsy (QOLIE)-31/P and Euro Quality of Life 5 Dimensions (EQ-5D) created a variation in predictive factors for poor health-related quality of life (HRQoL), thus suggesting that a holistic approach not limited to seizure control should be considered when treating people with epilepsy.


**Assessing the Impact of Self-reported Disease Stage and Symptom Burden on Falls in Members of an Online Parkinson’s Disease Community**
Presented: Movement Disorder Society (MDS) 2013
Primary Community: Parkinson’s disease (PD)
Sponsor: AbbVie

A cross-sectional survey was conducted through PatientsLikeMe to characterize the occurrence of falls, risk factors for falling, and the impact of falls across self-reported disease severity, and to identify explanatory predictors of falls in individuals with Parkinson’s disease. Health-related quality of life (HRQoL) and overall health status were more strongly correlated with mobility restrictions due to fear of falling than with the frequency of falls. This finding confirmed the negative psychosocial consequences of falling in patients with Parkinson’s disease.

• **Assessing the Impact of Self-Reported Disease Stage and Motor and Non-motor Symptom Burden on Health-related Quality of Life in Parkinson’s Disease**
  Presented: Movement Disorder Society (MDS) 2013  
  Primary Community: Parkinson’s disease (PD)  
  Sponsor: AbbVie

Parkinson’s disease (PD) is a chronic, progressive neurodegenerative disease characterized by a constellation of motor and non-motor symptoms, which differentially impact patients’ health-related quality of life (HRQoL) and overall health status. A cross-sectional survey was collected through PatientsLikeMe to characterize the relative burden of these symptoms and to identify predictors of HRQoL for patients with PD. The survey confirmed severity, motor, and non-motor symptom burden as important predictors of HRQoL in PD patients.


**2012**

• **Characteristics of Users of the Epilepsy Community of PatientsLikeMe: An Update**  
  Presented: American Academy of Neurology (AAN) 2012  
  Primary Community: Epilepsy  
  Sponsor: UCB Pharma

This poster described the main characteristics of patients in the PatientsLikeMe epilepsy community, as of May 2011. Cognitive problems, fatigue, and somnolence were found to be the most frequently reported problems in patients with epilepsy. The occurrence of seizures was associated with significant decrements in HRQoL and increased depression and anxiety levels.

• **An online MS research platform: How generalizable are its subjects and how valid are its tools?**
  
  Presented: American Academy of Neurology (AAN) 2012  
  Primary Community: Multiple Sclerosis  
  Collaborator: Brigham and Women’s Hospital  
  
  This study was an assessment of the validity of the PatientsLikeMe Multiple Sclerosis Rating Scale, revised (MSRS-R) by comparison with clinically validated tools, and the assessment of biases in the PLM MS population. The MSRS-R is a useful patient-reported outcome tool, showing good correlation with physician measures. Compared with the patients at the Partners MS Center, PLM members were younger, more educated, less often white, and more often female - small but statistically significant differences.


• **Relation of Body Mass Index and Disease Severity in an Online Multiple Sclerosis Population**
  
  Presented: European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS) 2012  
  Primary Community: Multiple Sclerosis  
  Collaborator: Brigham and Women’s Hospital  
  
  Multiple sclerosis (MS) may be mediated by metabolic factors, including body habitus and adipokines. This study explores the relationship between body mass index (BMI) and disease course in patients with MS. Of the included population, 58% of subjects were overweight or obese. However, there was a negligible association between BMI and the Multiple Sclerosis Rating Scale, either cross-sectionally or longitudinally.

**Patient-Reported Outcomes (PROs) in Safety Adverse Event Reporting – A New Framework**

Presented: International Conference on Pharmacoepidemiology (ICPE) 2012  
Primary Community: General  
Collaborator: Pope Woodhead & Associates

The Patient-Reported Outcomes Safety Event Reporting (PROSPER) Consortium was convened to champion Patient Reported Outcomes – Adverse Event (PRO-AE) as a novel source of useful safety data; to define a standard for validating PRO-AEs and information sources; and to define an effective process for PRO-AE use. The draft PROSPER guidance found that PROs are valuable for safety evaluation, risk management/post-authorization safety and efficacy studies, evaluating the effectiveness of risk minimization, improving patient treatment adherence, and enhancing public safety and risk communication.


**Illness Burden in Patients with ALS and Their Caregivers: A Web-Based Survey**

Presented: International Symposium on ALS/MND 2012  
Primary Community: Amyotrophic Lateral Sclerosis  
Sponsor: Biogen Idec

Amyotrophic lateral sclerosis (ALS) has been found to have a significant impact on the quality of life (QoL) of both patients and their caregivers. This study evaluates the association between the functioning of patients with ALS and their health-related QoL. It also compares different approaches to measuring functional impairment using a validated patient-reported online version of the ALS Functional Rating Scale-Revised (ALSFRS-R), and evaluates the association between the functioning of patients and their caregivers’ HRQoL.

2011

• Patient-reported Clinician Adherence to Epilepsy Performance Measures of Quality Care
  Presented: American Academy of Neurology (AAN)
  Primary Community: Epilepsy

This study explores the patient-reported physician adherence to quality measures for a population of patients with epilepsy. This study also compares different physician specialities in their level of adherence to quality measures. It was found that epileptologists performed more measures of quality care than neurologists and all other specialties. More referrals to epileptologists should be made and more education tailored to neurologists on managing epilepsy is needed.


• PatientsLikeMe, a Data-Sharing Online Community: Benefits for Patients with Epilepsy
  Presented: American Academy of Neurology (AAN)
  Primary Community: Epilepsy
  Sponsor: UCB Pharma SA, PatientsLikeMe

This study describes the self-reported benefits among patients with epilepsy sharing their health data with other patients with epilepsy through the PatientsLikeMe community. The benefit patients perceived as most useful was learning about a symptom or symptoms that they experienced. The patients willing to connect to other patients experienced a greater range of perceived benefits to their epilepsy management, social interactions, and quality of life.

• **Characteristics of Users of the Epilepsy Community of PatientsLikeMe.com and Comparison with a Representative Claims Database**
  Presented: American Academy of Neurology (AAN)
  Primary Community: Epilepsy
  Sponsor: UCB Pharma

This poster describes the sociodemographics and clinical characteristics of members of the PatientsLikeMe epilepsy community, compared to that of the PharMetrics claims database. Analysis showed that compared to PharMetrics, the PatientsLikeMe epilepsy community tends to provide an over-representation of patients who are female, aged 20-50 years, receiving polytherapy, and receiving newer anti-epileptic drugs (AEDs).


• **PatientsLikeMe Epilepsy Community: An Insight into Symptoms and Side Effects Reported Online by Patients with Epilepsy**
  Presented: International Epilepsy Congress (IEC) 2011
  Primary Community: Epilepsy
  Sponsor: UCB Pharma

The PatientsLikeMe platform provides simple and easy-to-use tools allowing patients with epilepsy to record, monitor, and share their symptoms in a systematic and standardized way. This poster describes the symptoms and side effects recorded by patients on the PatientsLikeMe online platform between January 2010 and September 2010. Both the symptom checklist and treatment-associated side effects indicated that cognitive problems, fatigue, and somnolence were the most frequently reported problems in patients with epilepsy.

The PatientsLikeMe Epilepsy Community: A Unique Insight into the Lives of Patients with Epilepsy

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR) 2011
Primary Community: Epilepsy
Sponsor: UCB Pharma

The objectives of this study are to describe key characteristics of members of the online, USA-based, PatientsLikeMe epilepsy community, by comparison with a widely-used USA claims database, PharMetrics, and to assess the impact of epilepsy on patients’ lives using patient-reported data, collected through PatientsLikeMe. The PatientsLikeMe epilepsy community tends to provide an over-representation of patients who are female, aged 20-50 years, receiving polytherapy, and receiving newer AEDs. Analysis of PROs showed lower HRQoL and higher levels of anxiety and depression in patients who had experienced a seizure in the 4 weeks before assessment and patients who do not drive or who drive with limitations.


A Comparison of the PatientsLikeMe Quality of Life Questionnaire (PLMQOL) with the RAND SF-36

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR) EU 2011
Primary Community: General

This study provides an assessment of the PatientsLikeMe Quality of Life Questionnaire (PLMQOL) by comparing with the RAND SF-36 in a population of patients with chronic disease. The PLMQOL demonstrated high reliability across domains of physical function, mental function, and social function, and was highly correlated with relevant domains of the RAND SF-36. Thus, the PLMQOL is a reliable and valid instrument for online assessment of health-related quality of life.

Slawsky KA, Massagli MP, Wicks P (2011) A Comparison of the PatientsLikeMe Quality of Life Questionnaire (PLMQOL) with the RAND SF-36, Value in Health, 14(7):A426
• **Development and Validation of the Multiple Sclerosis Rating Scale Revised (MSRS-R)**  
  Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR) EU 2011  
  Primary Community: Multiple Sclerosis (MS)

The Multiple Sclerosis Rating Scale (MSRS) was developed to measure functional status for MS patients longitudinally. Through cognitive debriefing, the MSRS was improved with the addition of a bladder and bowel dysfunction item and with minor language changes to create the MSRS (Revised) version, the MSRS-R. It was deployed as a cross-sectional survey to 4,382 patients with relapsing-emitting MS on the PatientsLikeMe platform. From the 816 MS patients that responded, it was found that the MSRS-R exhibited high internal consistency, the walking item was highly correlated with alternative walking measures, and it correlated well with comparison instruments. It reliably differentiated between participants by patient determined disease steps (PDDS) disease stage, relapse severity, and time since diagnosis.

Wicks P, Vaughan TE, Massagli MP (2011) Development and Validation of the Multiple Sclerosis Rating Scale (MSRS-R), Value in Health, 14(7):A325 (Top 10% of abstracts award at ISPOR Europe)

• **Development of a Self Report Bulbar Function Scale (CNS-BFS)**  
  Presented: American Academy of Neurology (AAN) 2011  
  Primary Community: Amyotrophic Lateral Sclerosis (ALS)  
  Collaborator: Center for Neurologic Study

The CNS-BFS (Center for Neurologic Study Bulbar Function Scale) is a self-report scale that has been developed for use as an end point in clinical trials and as a clinical measure for evaluating and following ALS patients. The CNS-BFS assesses swallowing, speech and salivation. It was highly correlated with Global Impression Scale, thus it is a valid assessment of bulbar function in ALS patients.

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

  Presented: American Academy of Neurology (AAN) 2011
  Primary Community: Multiple Sclerosis (MS)
  Sponsor: Novartis

  Patients taking needle-based disease modifying therapies (DMTs) to treat MS may be faced with a range of barriers to being fully adherent. This poster outlines the development of a scale to measure the barriers to DMT adherence in patients with MS and looks at initial findings. The MS Treatment Adherence Questionnaire (MS-TAQ) is a self-report questionnaire that quantifies the differing profiles of barriers to adherence and quantifies the degree of non-adherence across patients with different daily dosing regimes.


  **2010**

  • **Limb Dominance and Laterality of Onset in ALS: A Pathogenic Role for Exercise or Clue to a Cortical Vulnerability**

  Presented: ALS/MND International Symposium 2010
  Primary Community: Amyotrophic Lateral Sclerosis (ALS)
  Collaborator: University of Oxford

  This study explores how exercise influences the development of ALS. A group (N=343) of patients with limb-onset amyotrophic lateral sclerosis (ALS) patients from PatientsLikeMe were asked to assign their handedness and footedness, followed by limb of first weakness. The side of onset in upper limb-onset ALS is concordant with handedness but no concordance for side of onset and footedness was found.

• **Development of a Scale to Measure Barriers to Disease-Modifying Therapy Adherence in MS**
Presented: Consortium of Multiple Sclerosis Centers (CMSC) 2010  
Primary Community: Multiple Sclerosis (MS)  
Sponsor: Novartis

Patients with multiple sclerosis (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. The aim of this study is to quantify the degree of non-adherence across patients with different daily dosing regimes and to develop a self-report questionnaire, The MS Treatment Adherence Questionnaire (MS-TAQ), to quantify the differing profiles of barriers to adherence. It was found that between 8-51% of patients reported missing at least one dose of the DMT in the previous 28 days and the number of missed doses in that time period is dependent on the treatment.

Wicks P, Massagli M, Kulkarni A, Dastani H. Development of a scale to measure barriers to disease-modifying therapy adherence in MS. Programs and abstracts of the 2010 Annual Meeting of the Consortium of Multiple Sclerosis Centers; Abstract S145.

• **Characteristics of an Online Renal Data-Sharing Initiative: The PatientsLikeMe Transplants Community**
Presented: ALS/MND International Symposium 2010  
Primary Community: Organ Transplant  
Sponsor: Novartis

This poster presents descriptive data from the PatientsLikeMe organ transplant community and compares it to the mandatory reporting data from the US Organ Procurement and Transplantation Network. The authors concluded that the transplant community at PatientsLikeMe is a growing community that provides education and social support and may advance scientific and medical research.

• Characteristics of Users of the Epilepsy Community of PatientsLikeMe.com and Comparison with a Representative Claims Database

Presented: American Epilepsy Society (AES) 2010
Primary Community: Epilepsy
Sponsor: UCB Pharma

This poster describes the sociodemographic and clinical characteristics of members of the PatientsLikeMe epilepsy community, and compares this community to that of the representative claims database, PharMetrics, community. Analysis showed that compared to PharMetrics, the PatientsLikeMe epilepsy community tends to provide an over-representation of patients who are female, aged 20-50 years, receiving polytherapy, and receiving newer AEDs.


2009

• Pseudobulbar Affect: Better Understanding Through Research on a Social Network

Presented: 2009 ALS/MND Symposium
Primary Community: ALS
Sponsor: Avanir

Pseudobulbar affect (PBA) involves exaggerated or involuntary emotional outbursts and occurs in patients with degenerative neurological conditions such as ALS and MS. This study utilized a survey to explore how well ALS patients understand PBA, its association with ALS, and how likely they are to report their cognitive symptoms to their physicians.

Wicks P, Kaye R (2009) Pseudobulbar affect: better understanding through research on a social network, Amyotrophic Lateral Sclerosis, 10(5):169
• **An internet-based approach to genetic data discovery in ALS**  
Presented: 2009 ALS/MND Symposium  
Primary Community: ALS

Many patients with Familial ALS (FALS) are unaware of their specific genetic mutation and the implication of that mutation to their prognosis. In efforts to provide patients the opportunity to share their genetic information and allow further data collection in regards to familial ALS, additional fields were added to the ALS condition history on PatientsLikeMe.com to allow the addition of genetic test results to patients that report having FALS. There is a need for more data to compare how specific mutations affect the disease progression, thus a system that rewards genetic data with better predictive ability may drive demand for genetic testing.


**Internet-based observational study finds no impact of lithium on ALSFRS-R progression**  
Presented: 2009 ALS/MND Symposium  
Primary Community: ALS

A small clinical trial had reported that lithium carbonate delayed the progression of ALS, prompting many patients to begin taking lithium. We present results of our observational study in which we found no such impact. The study introduced our “matching algorithm”, by which we reduce the progression bias between patients who reported lithium use, and those who did not. (See also lithium poster from 2008 for more background.)

2008

**Prevalence of Non-Motor Symptoms amongst Parkinson’s Disease Users in an Online Health Community**
Presented: Movement Disorders Society (MDS) 2008
Primary Community: Parkinson’s disease

To evaluate whether or not patients with Parkinson’s disease are more likely to report non-motor symptoms online than through conventional means, the validated Non-Motor Symptom Questionnaire (NMS-QUEST) was administered online on PatientsLikeMe.com. The results showed there was a high discrepancy between PatientsLikeMe members and previous literature on changes in sex drive, insomnia, unexplained pains, and digestive problems. It was found that patients are more likely to truthfully report these symptoms online.

Wicks P, Martinez-Martin P, Chaudhuri RK (2008) Prevalence of non-motor symptoms amongst Parkinson’s disease users in an online health community (PatientsLikeMe.com), Movement Disorders, 23:S1, S332

**Pathological Gambling and Hobbyism amongst Internet Users: Comparison of Parkinson’s Disease and ALS/MND**
Presented: Movement Disorders Symposium (MDS) 2008
Primary Community: Parkinson’s disease and amyotrophic lateral sclerosis/motor neuron disorders (ALS/MND)

This study evaluated and compared pathological gambling (PG) in patients with Parkinson’s disease and patients with ALS using an online survey on PatientsLikeMe.com. This study found that patients with Parkinson’s disease were twice as likely to report a disruptive hobby and were more likely to have PG when compared to patients with ALS (13% to 3%, respectively).

Online Data-Sharing Community for Patients with Parkinson’s: PatientsLikeMe
Presented: Movement Disorders Symposium (MDS) 2008
Primary Community: Parkinson’s disease

PatientsLikeMe is a web-based system that serves as a community for patients with similar diseases, experiences and treatments. In addition, PatientsLikeMe provides a platform of tools for both disease tracking and research across disease states. This poster presents key features, current Parkinson’s disease patient usage statistics, and future enhancements for the website.


A Patient-led Trial of Lithium In ALS Using the Internet
Primary Community: ALS

In 2007, an Italian study reported that ALS patients taking lithium were able to slow the progression of their disease. As of 2008, over 160 ALS patients were tracking their use of lithium and reporting the disease progression and side effects on PatientsLikeMe.com. Lithium was found to have no significant positive effect on average. No significant difference was found between patients who took riluzole in addition to lithium compared to those who only took lithium.

2007

Telesocial Medicine for Neurological Disorders – PatientsLikeMe
Presented: British Neuropsychiatry Association (BNPA) 2007
Primary Community: General

PatientsLikeMe is a web-based system that serves as a platform for disease tracking and a community for patients with similar diseases, experiences and treatments. It also serves as a research platform for cross-disease studies. This poster presents key features, current usage statistics, and future developments for the website. It is currently used for patients with Motor Neuron Disease/Amyotrophic Lateral Sclerosis (MND/ALS) but is expanding to other diseases.