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2025

Longitudinal Survey of Adult Patients with Hereditary Angioedema Receiving Long-Term Prophylaxis for 3 Years or Longer with Lanadelumab: Baseline Findings

Presented: American Academy of Allergy, Asthma, and Immunology (AAAAI)

Primary Community: Hereditary Angioedema

The goals of this study were to examine the quality of life (well-being, productivity and/or activity, disease control) among adults diagnosed with HAE with C1 inhibitor deficiency (HAE-C1INH)-Type 1 or Type 2 treated with lanadelumab LTP in real-world clinical practice. Baseline findings included self-reported data from 41 patients through the PatientsLikeMe online platform and were developed using insights gained from qualitative interviews with 6 patients who were receiving lanadelumab for HAE. In this patient-centric study, lanadelumab LTP was associated with reduced HAE attack frequency/severity, improved QoL, and high treatment satisfaction. All patients reported immediate or rapid incremental improvements in their HAE after starting lanadelumab treatment, with most patients reporting full or partial relief of HAE symptoms.

> Driscoll Shempp P, Banerji A, Kirby M, Mamey MR, Singh D, D Fox, Juethner S (2025) Longitudinal Survey of Adult Patients with Hereditary Angioedema Receiving Long-Term Prophylaxis for 3 Years or Longer with Lanadelumab: Baseline Findings. American Academy of Allergy, Asthma, and Immunology (AAAAI), San Diego, CA, United States, Feb 28 – March 3, 2025 (Poster).

2024

24-Week Results From a PatientsLikeMe Observational Study: Vortioxetine vs Standard of Care Antidepressants in Major Depressive Disorder

Presented: Psych Congress and Neuroscience Education Institute (NEI) Congress

Primary Community: Major Depressive Disorder

The primary objective of the study is to assess the Patient Overall Global Impression of Improvement (PGI-I) in patients on vortioxetine at 12 weeks compared to other monotherapy antidepressant treatments following a new start or switch. Secondary objectives include measuring changes between groups in MDD symptoms and severity, cognitive impairment, functioning, wellbeing, emotional blunting, resiliency, medication satisfaction, quality of life (QOL), goal attainment and patient engagement. Among 503 patients, mean age was 47.4 years, 58.4% were female, 62.4% were White, and 67.4% were Not Hispanic/Latino. On week 24, 87% (132/151) of patients in the vortioxetine and 91% (322/352) in the other SOC group completed the survey. Participants in the vortioxetine group reported a greater improvement in depression and higher treatment efficacy at week 24, as indicated by their PGI-I scale scores, since starting their medication compared with those in the other SOC AD group. Although both groups exhibited

improvements in depressive symptoms, the vortioxetine group achieved significantly higher remission rates compared with the other SOC AD group, as measured by PHQ-9 scores. Greater improvements in overall well-being and life satisfaction were observed among participants in the vortioxetine group compared with the other SOC AD group. A difference observed at 12 weeks and maintained at 24 weeks.

Burke K, Blair C, Parikh S, McIntyre R, Opler M, Macarayan E, Bispham J, Karim A, Martin M, Driscoll-Shempp P, Robinson I, McCue M (2024) 24-Week Results from a PatientsLikeMe Observational Study: Vortioxetine vs Standard of Care Antidepressants in Major Depressive Disorder. Psych Congress, Boston, MA, United States, Oct 29 - Nov 2, 2024 (Poster)

Burke K, Blair C, Parikh S, McIntyre R, Opler M, Macarayan E, Bispham J, Karim A, Martin M, Driscoll-Shempp P, Robinson I, McCue M (2024) 24-Week Results from a PatientsLikeMe Observational Study: Vortioxetine vs Standard of Care Antidepressants in Major Depressive Disorder. Neuroscience Education Institute, Colorado Springs, CO, United States, Nov 7 - 10, 2024 (Poster)

Longitudinal Survey of Adult Patients with Hereditary Angioedema Receiving Long-Term Prophylaxis with Lanadelumab.

Presented: American College of Allergy, Asthma, & Immunology (ACAAI)

Primary Community: Hereditary Angioedema

The goals of this study were to evaluate the treatment journey of adult patients with HAE receiving long-term prophylaxis (LTP) with lanadelumab through qualitative interviews (phase I) and to inform the design and development of quantitative surveys (phase II). Six patients (83% female) with Type I or Type II HAE and taking lanadelumab continuously for three years or more were interviewed to better understand the patient's treatment journey using patient-centric themes, including topics quality of life, experience with diagnosis and living with HAE, disease burden, perceptions of well-being, treatment experience/satisfaction, and treatment goals. Patients generally reported that, prior to receiving lanadelumab, they faced challenges in managing activities of daily living, given the unpredictability of HAE attacks and attack severity. Overall, patients reported an improvement in their quality of life after receiving lanadelumab. Most patients reported reduced anxiety about the unpredictability of HAE attacks after receiving lanadelumab, with most reporting their lives returned to relative normality. Patients had an optimistic outlook and noted that current treatments for HAE have made the condition manageable.

Banerji, A, Driscoll Shempp P, Mamey MR, Kirby M, Singh D, Macarayan E, Fox D, Juethner S (2024) Longitudinal Survey of Adult Patients with Hereditary Angioedema Receiving Long-Term Prophylaxis with Lanadelumab. American College of Allergy, Asthma, & Immunology, Boston, MA, United States, Oct 24 – 28, 2024 (Poster).

Vortioxetine Vs Other Standard of Care Antidepressants in Patients With Major Depressive Disorder: 12-Week Interim Analysis From PatientsLikeMe Survey

Presented: American Society of Clinical Psychopharmacology (ASCP)

Primary Community: Major Depressive Disorder

The primary objective of the study is to assess the Patient Overall Global Impression of Improvement (PGI-I) in patients on vortioxetine at 12 weeks compared to other monotherapy antidepressant treatments following a new start or switch. Secondary objectives include measuring changes between groups in MDD symptoms and severity, cognitive impairment, functioning, wellbeing, emotional blunting, resiliency, medication satisfaction, quality of life (QOL), goal attainment and patient engagement. Among 503 patients, mean age was 47.4 years, 58.4% were female, 62.4% were White, and 67.4% were Not Hispanic/Latino. At week 12, 89% (134/151) of patients in the vortioxetine and 97% (343/352) in the other SOC group completed the survey. At week 12, 4.47% of patients in the vortioxetine and 1.75% in the other SOC group reported improvement in PGI-I scores, but this was not statistically significant (P=0.83). At the same time, vortioxetine patients with a change 3-6 months prior to study reported significantly better PGI-I scores vs the other SOC group (3.5 vs 3.9; P=0.01). Numerically improved mean scores were observed in the vortioxetine vs other SOC group for PDQ-D5 (7.74 vs 8.49; P=0.09), WHO-5 (11.42 vs 9.62; P<0.001), and Q-LES-Q-SF (49.27 vs 47.61; P<0.05). No statistically significant difference was observed in PHQ-9 scores, but remission rate (PHQ-9 score <5 at week 12 follow-up) was higher in the vortioxetine (n=12) vs other SOC group (n=8; χ^2=8.94, df=1; P<0.01).

Burke K, Blair C, Parikh S, McIntyre R, Opler M, Macarayan E, Bispham J, Karim A, Martin M, Driscoll-Shempp P, Robinson I, McCue M (2024) Vortioxetine Vs Other Standard of Care Antidepressants in Patients with Major Depressive Disorder: 12-Week Interim Analysis from PatientsLikeMe Survey. American Society of Clinical Psychopharmacology, Miami Beach, Florida, United States, May 28-31, 2024 (Poster)

2023

Survey of Diagnostic Journey, Treatment, Experience, And Impact on Daily Living of Patients with Alpha-1 Antitrypsin Deficiency

Presented: American Thoracic Society (ATS) Conference
Primary Community: Alpha-1 Antitrypsin Deficiency patients

The main goal of this study was to gain insights, characterize, and better understand the diagnostic journey and experience of patients living with Alpha-1 Antitrypsin Deficiency. Forty-three patients with a mean age of 37 years and 48.8% White with self-reported AATD participated in the cross-sectional survey. The survey participants consulted an average of 3 healthcare professionals before receiving their AATD diagnosis and approximately half of them were diagnosed by a pulmonologist. Of the 43 participants, 24 of them had to wait for a mean time of 6.9 years to receive a final diagnosis of AATD. Results indicate that patients with AATD are commonly misdiagnosed for years until worsening symptoms begin to impact their daily life. Many people wished that they had been aware of their condition earlier so they could have received proper treatment, taken charge to manage their symptoms earlier and taken precautions such as avoiding

environmental agitators. Most participants reported having good communication with their healthcare providers and believed they could set realistic AATD management goals. Participants reported that their current symptoms, while well managed, did impact their day-to-day lives.

Blair C, Raveendran S, Burke M, Singh D, Karim A, McAuliffe-Fogarty A, Macarayan E, Hogarth K, Hinson J, McCue M (2023) Survey of Diagnostic Journey, Treatment, Experience, And Impact on Daily Living of Patients with Alpha-1 Antitrypsin Deficiency. American Thoracic Society, Washington D.C, United States of America, May 19-24, 2023 (Poster)

Understanding Cytomegalovirus Symptom Management, Quality of Life, and Care Coordination in Transplant Recipients Through Patient and Care Partner Experiences

Presented: IDWeek Conference
Primary Community: Transplant patients and caretakers

The purpose of this study was to better understand patient and care partner knowledge of CMV and their post-transplant (SOT and HCT) experience, and to identify knowledge gaps and opportunities to educate transplant recipients and care partners. Twenty-nine participants completed the survey with a mean age of 48.1 years, 32.1% female, 90.3% single organ transplant (SOT), and 50% diagnosed with CMV post-transplant. Most participants reported a positive experience with their care team post-transplant surgery but expressed they were not well-informed about CMV infection post-transplant. More than half were unaware of their own or their donor's CMV status prior to transplant and most reported challenges remembering to take their medications as prescribed, the burden of clinic visits, monitoring the impact of side effects, and coordinating various medications and supplements. The post-transplant care journey could be improved by better preparing and educating transplant recipients and care partners about CMV and its management.

Singh D, Burke K, Raveendran S, Macarayan E, Razzaque M, Papanicolaou G, Levan M, McCue M, Gower M, Gelone D (2023) Understanding Cytomegalovirus Symptom Management, Quality of Life, and Care Coordination in Transplant Recipients Through Patient and Care Partner Experiences. IDWeek, Boston, MA, United States, Oct 11-15, 2023.

2018

Characteristics and Symptom Severity in 21,101 Patients Reporting Systemic Erythematosus in the PatientsLikeMe Online Health Community

Presented: American College of Rheumatology (ACR) Conference
Primary Community: Systemic lupus erythematosus

The primary objective of this research was to characterize the PLM SLE population by their initial reported patient characteristics. Of 21,101 patients who met the inclusion criteria, the median age was 46 years, and the majority were female. Most were U.S. residents, and the patients who recorded race were predominantly Caucasian (67.8%) and African-American (22.4%). The most commonly reported comorbidities were fibromyalgia, discoid lupus, and lupus nephritis. The age, gender andrace of SLE patients in the PatientsLikeMe community are broadly consistent with what is known about the US SLE population. The PLM SLE population provides a unique source of real-world information on the patient's experience of symptoms of SLE outside the clinical environment that can be utilized to improve understanding of SLE.

> Nyman E, Hammond E, Vaughan T, Desta B, Wang X, Volkan Barut V, Emmas C (2018). Characteristics and Symptom Severity in 21,101 Patients Reporting Systemic Lupus Erythematosus in the PatientsLikeMe Online Health Community. American College of Rheumatology Conference, Chicago, IL, USA, October 19-24, 2018 (Poster)

How Do Patients Describe Their "New Normal" in Systemic Lupus Erythematosus? Use of Probabilistic Topic Modeling to Characterize Patients' Experiences Recorded in an Online Health Community

Presented: American College of Rheumatology (ACR) Conference
Primary Community: Systemic lupus erythematosus

The goal of this research was to understand patients' new way of living with SLE, outside of a clinical setting. Topics related to the new normal in SLE were studied by analyzing free text data from patients self-reporting a diagnosis of SLE on PLM. 138,409 free-text SLE-related posts from 15,060 users on PatientsLikeMe were analyzed using a natural language processing model called latent Dirichlet allocation (LDA). Patients reported feeling overwhelmed by pain and fatigue. Patients describe a constant struggle to overcome isolation and communicate their feelings to their family, friends, health care providers (HCPs), and employers. In addition, pain management strategies from physicians felt largely ineffective, as do many drug treatments. Patients struggled with the unpredictability of these symptoms and conveyed a sense of resignation and acceptance to this new normal. They accepted that many daily activities (e.g. taking a shower or housework) would never be easy again and adapted to their lives accordingly. However, patients also use the online community to help support each other in their shared experiences with SLE.

> Eaneff S, Vaughan T, Barut V, Havsol J, Nohe B, Emmas C (2018). How Do Patients Describe Their "New Normal" in Systemic Lupus Erythematosus? Use of Probabilistic Topic Modeling to Characterize Patients' Experiences Recorded in an Online Health Community. American College of Rheumatology Conference, Chicago, IL, USA, October 19-24, 2018 (Poster)

A Patient-Derived Conceptual Framework of Lung Cancer Care Priorities

Presented: ASCO Quality Care Symposium
Primary Community: Lung Cancer

The objectives of this study were to understand lung cancer care priorities from the patient's perspective, and to compare these priorities between patient subgroups. Lung cancer patients from the PatientsLikeMe online community participated in two phases of this study using the group concept mapping method. First, patients generated ideas in response to this question: "What do you want to achieve when it comes to the treatment you are receiving or are considering receiving for your lung cancer?" Next, patients were asked to group those concepts (78) into as many categories that made sense to them, and to rate importance on a scale of 1 to 5, with 5 as most important. After analysis, the ideas fell into 11 different categories ranging from supportive environment (average score: 4.01) to managing lifestyle (highest average score: 4.52). As this study was patient-driven, it helped inform the value of different aspects of care such as treatment goals, quality of life and care team.

Mujumdar U, Lanzarini V, Lowe M, Bolinder B, Doleh Y. (2018). A Patient-Derived Conceptual Framework for Lung Cancer Care Priorities. ASCO Quality Care Symposium, Phoenix, AZ, USA, September 28-29, 2018 (Poster)

Assessment of Patient-Initiated Adverse Event Reports Received by the Food and Drug Administration from PatientsLikeMe

Presented: International Conference on Pharmacoepidemiology
Primary Community: Regulators, Drug Safety, Pharmacoepidemiology

Adverse event reports that are initiated by patients through a platform such as PatientsLikeMe that are screened for completeness and then submitted to the FDA Adverse Event Reporting System (FAERS) database contain sufficient case details to meet the FDA requirements for inclusion in the FAERS database and could potentially contribute to pharmacovigilance activities.

Brajovic S, Okun S, Sahoo S, Hall M, Pamer C. 2018 Assessment of Patient-Initiated Adverse Event Reports Received by the Food and Drug Administration from PatientsLikeMe. International Conference on Pharmacoepidemiology, Prague, Czech Republic August 22-26, 2018 (Poster)

Thrive – A Human-Centered Universal PRO System for Self-Management, Digital Discovery, and Personalized Medicine

Presented: International Society for Quality-of-Life Research (ISOQOL) 25th Annual Conference
Primary Community: All

Since its inception, PatientsLikeMe has offered patients with chronic health conditions a range of patient reported outcome (PRO) questionnaires to help them track their progress, share their data, and contribute

to research. However, traditional PROs have shortcomings like feeling long, burdensome, and depressing to complete because they are negatively framed. Patients with multiple comorbidities (which are most of our members) have to complete multiple PROs to capture their experience, which is very burdensome. We sought to address these shortcomings by developing a new modular, universal measurement system ("Thrive") that was intended for digital tools. Initial validation of the core items fielded to all patients suggested satisfactory psychometric performance, and future research will focus on condition-specific versions of the Thrive instrument.

Chiauzzi E, Wicks P, McCaffrey S, Goodwin K, Black R, Hoole M, Heywood J. (2018). Thrive – A Human-Centered Universal PRO System for Self-Management, Digital Discovery, and Personalized Medicine. International Society for Quality-of-Life Research (ISOQOL) 25th Annual Conference, Dublin, Ireland, October 24-27, 2018 (Poster)

Use of Patient-Reported Data to Detect Medication Errors

Presented: International Conference on Pharmacoepidemiology & Therapeutic Risk Management
Primary Community: All

The US Food and Drug Administration (FDA) continuously explores new data sources to support regulatory science research. Through this project, FDA and PLM explored the use of patient-generated health data (PGHD) to detect medication errors in order to look at the types of errors described and whether the data contained sufficient information for analysis. During review, we identified 206 free text posts that contained one or more medicAug 2018ation errors; 14 unique posts contained 16 medication errors potentially relevant to FDA. However, the posts did not contain sufficient information for analysis. The study demonstrated that a PGHD platform like PLM may capture medication error information, but the errors described may lack sufficient information to warrant regulatory action.

Zisk M, Leutner R, Brajovic S, Eaneff S, Thompson A, Farhadi Jones G, Okun S, Hall M, Pamer C. (2018). Use of Patient-Reported Data to Detect Medication Errors. International Conference on Pharmacoepidemiology & Therapeutic Risk Management, Prague, Czech Republic, August 22-26, 2018 (Poster)

Comparing Two Drug Treatment Coding Approaches: Coding Challenges and Lessons Learned

Presented: Drug Information Association (DIA) 2018 Global Annual Meeting
Primary Community: All

Both PatientsLikeMe and the FDA use drug dictionaries to capture drug treatments consistently. This review compared the drug dictionaries used by PatientsLikeMe, a platform for tracking and sharing patient-generated health data (PGHD) and the FDA Product Dictionary (FPD) to identify and understand any

differences that might exist between the two databases. The analysis led to recommendations for improving PLM's database, such as back-end mapping to validated name-substance pairs for prescription and over-the-counter medications utilizing the RxTerms database. Although not the same, the PLM and FDA drug dictionaries can be bridged through a hybrid automated – manual method, particularly for prescription and over-the-counter treatments.

Chang S, Blaser DA, Lowe M, Brajovic S, Okun S, Hall M, Pamer C. (2018). Comparing Two Drug Treatment Coding Approaches: Coding Challenges and Lessons Learned. Drug Information Association 2018 Global Annual Meeting, Boston, MA, USA, June 24-28, 2018 (Poster)

2017

Attitudes on Goals in Depression

Presented: American Academy of Family Practitioners (AAFP) Family Medicine Experience
Primary Community: Major Depressive Disorder (MDD)

Although major depressive disorder (MDD) is a highly prevalent disorder, frequently diagnosed and treated in a primary care setting, little information is available regarding the treatment decision process between MDD patients and providers. This study sought to explore treatment goal-setting experiences of MDD patients, including whether patients set goals for treatment and if so, the types of treatment goals that were important to them. In addition, the role of the clinician in establishing treatment goals, factors motivating patients when seeking a medication switch, and the extent to which patients felt their goals reflected SMART criteria were evaluated. Finally, patients were asked to reflect on a goal attainment approach used for establishing and tracking progress towards treatment goals that are meaningful to individual patients.

McNaughton E, Granskie J, Curran C, Opler M, Sarkey S, Schuster J, Mucha L, Eramo A, Franqois C, Webber-Lind B, McCue M. (2017). Attitudes on Goals in Depression. AAFP Family Medicine Experience, San Antonio, TX, USA, September 12-16, 2017 (Poster)

Final results from an open-label, single-center, hybrid-virtual 12-month trial of Lunasin for patients with ALS

Presented: 28th International Symposium on ALS/MND 2017
Primary Community: ALS

Lunasin is a soy-derived peptide suggested as having reversed a single and well-publicized case of ALS. Following a review by ALS Untangled we collaborated with Duke University Medical Center to conduct an open-label hybrid virtual trial of Lunasin using historical controls on PatientsLikeMe. We enrolled 50 participants in 5.5 months, with overall survivor retention of 84% at the final 12-month study visit. Three matched control participants were identified for each treated patient, and unfortunately, we found no evidence of slowing disease. There were seventeen adverse events including two serious (constipation

requiring hospitalization). We found no evidence that Lunasin can slow ALS but found our virtual trial approach to be acceptable to patients and to yield useful data.

Bedlack R, Spector A, Morgan E, Wicks P, Vaughan T, Blum R, Dios A, Sadri-Vakili G. (2017). Final results from an open-label, single-center, hybrid-virtual 12-month trial of Lunasin for patients with ALS. 28th International Symposium on ALS/MND 2017, Boston, MA, USA, December 8-10, 2017 (Poster)

Facilitating data transfer from a patient community to the ALS Online Genetics Database (ALSoD)

Presented: 28th International Symposium on ALS/MND 2017
Primary Community: ALS

The ALS online database (ALSoD) is a freely available, user-friendly online bioinformatics tool for ALS genetics research. ALSoD combines genotype, phenotype, and geographical information to allow clinicians and researchers to better understand specific mutations. To date most information has been harvested from scientific literature, online databases, or submissions from clinicians. PatientsLikeMe is a free online community for patients with ALS to track their disease progression, connect with other patients like them, and contribute their shared health data (including familial history and, in some cases, genetics) with researchers. In the present study we sought to begin exporting patient-reported genetics data from our ALS community into ALSOD. There were 661 variants reported from 1096 patients in the ALSoD database with complete age of onset, gender, site of onset and geographical information, and 5 variants from 97 patients reporting a positive familial ALS gene test in the PatientsLikeMe data. Future work will further integrate the two datasets.

Wicks P, Cerrato D, Martin S, Kulka A, Abel O, Al-Chalabi A. (2017). Facilitating data transfer from a patient community to the ALS Online Genetics Database (ALSoD). ALS. 28th International Symposium on ALS/MND 2017, Boston, MA, USA, December 8-10, 2017 (Poster)

"Freed by a wheelchair" – How patients use and experience their power wheelchairs

Presented: 28th International Symposium on ALS/MND 2017
Primary Community: ALS

As their mobility deteriorates, people with ALS (PALS) increasingly rely on mobility aids and devices to maintain their independence. As their needs increase, power wheelchairs are increasingly becoming platforms for other assistive technologies such as communication devices, ventilators, or environmental control mechanisms. Innovations such as GPS, integration of cellular services, and Bluetooth offer possible enhancements but also raise privacy concerns. Using database analysis and a survey we found that >80% of patients reported moderate or major efficacy of power wheelchairs to address their fatigue, lack of mobility, and balance problems, noting that wheelchairs help them to regain independence and minimize the risk of injury. Patients appear enthusiastic about the potential for newer forms of "connected wheelchairs" but want transparency and control over how their data is shared. Engaging online with patients in product R&D may be an efficient way of developing better products and services to meet patient needs.

Wicks P, Cerrato D, Eaneff S, Leire K, Andersson-Svahn H. (2017). "Freed by a wheelchair" – How patients use and experience their power wheelchairs. 28th International Symposium on ALS/MND 2017, Boston, MA, USA, December 8-10, 2017 (Poster)

Major depressive disorder patients reflect on proposed US health care policy changes

Presented: American Public Health Association
Primary Community: All

Patients with MDD are less likely to support reduction of ACA coverage than other chronically ill patients and the general population (when compared to other polls). The impacts of changes to the ACA may disproportionately and negatively affect health care services for MDD.

Fitz-Randolph M, Curran C, Xiao S. (2017). Major depressive disorder patients reflect on proposed US health care policy changes. American Public Health Association, Atlanta, GA, USA, November 4-8, 2017 (Poster)

Monitoring Physical Activity Using a Wearable Device in Pompe Disease

Presented: 22nd International Congress of the World Muscle Society
Primary Community: Pompe disease

Pompe patients felt that nutrition and physical activity were the most important parameters that they should self-monitor and were particularly interested in monitoring devices that tracked respiratory function, nutrition, and physical activity. Data from this pilot study allowed researchers to categorize patients based on patterns of activity reported from trackers, which is a new way to follow a patient's condition. Measured activity (step count and intensity) was greater in patients who were younger, male, had disease onset in adult life, less time since disease onset, less time between initial symptoms and diagnosis, not requiring walking aids, and least severe symptoms as measured by the Pompe Disease Symptom Scale.

Hamed A, Curran C, Dasmahapatra P. (2017). Monitoring Physical Activity Using a Wearable Device in Pompe Disease. 22nd International Congress of the World Muscle Society, Saint Malo, France, October 3-5, 2017 (Poster)

Provider Interactions and Cost Affect Type 2 Diabetes Mellitus Patients' Perceptions of Care Quality and Adherence

Presented: American Diabetes Association 77th Scientific Sessions
Primary Community: Type 2 Diabetes

Adherence to treatment for Type 2 Diabetes Mellitus (T2DM) is influenced by both the quality-of-care people receive and the cost of treatment. This study used a cross-sectional survey of 296 people with T2DM to describe their perceptions of quality care and the impact of out-of-pocket (OOP) costs. Participants reported that high quality care means that providers listen carefully, explain things in a way they can understand, and spend enough time with them. About one in five (19%) of all participants said they had used less medication than prescribed due to OOP costs. Among those who had made personal financial changes due to the cost of T2D treatment, only 42% had discussed the cost of their treatment with their doctor. Among those who did discuss OOP costs with their provider, over half (63%) changed their medication as a result. More discussions between patients and providers about cost may help improve adherence by facilitating affordability of treatment.

Simacek K, Schutt T, Darden N, Emmas C, Haggert L, Aharon S, Hanger M. (2017).
Provider Interactions and Cost Affect Type 2 Diabetes Mellitus Patients' Perceptions of Care Quality and Adherence. American Diabetes Association Annual Conference, San Diego, CA, USA, June 9-13, 2017 (Poster)

Treatment Satisfaction and Burden of Illness with Oral vs Injectable Therapy in Patients with Relapsed/Refractory Multiple Myeloma (RRMM)

Presented: ISPOR 22nd Annual International Meeting
Primary Community: Multiple Myeloma

This project describes a head-to-head comparison on treatment satisfaction, patient productivity and burden of illness (economic and time) of oral vs. injectable (with or without oral) treatments in multiple myeloma in relapsed/refractory patients. A convenience sample of 124 patients with self-reported multiple myeloma completed a cross-sectional survey containing measures of treatment satisfaction, performance status, fragility, and burden of illness. Emerging data suggests that an all-oral regimen is associated with a higher level of treatment convenience and lower healthcare resource use than an injectable regimen in RRMM. There is a significant patient and caregiver burden in both cost and time among injectable users. Alternate modes of administration may be considered to reduce this burden.

Romanus D, DasMahapatra P, Hoole M, Lowe M, Curran C, Campbell S, Bell J A. (2017). Treatment Satisfaction and Burden of Illness with Oral vs Injectable Therapy in Patients with Relapsed/Refractory Multiple Myeloma (RRMM). ISPOR 22nd Annual International Meeting, Boston, MA USA, May 20-24, 2017 (Poster)

Development of a Conceptual Framework of "Good Healthcare" from The Patient's Perspective

Presented: ISPOR 22nd Annual International Meeting
Primary Community: Various

The primary objective of this study was to conceptualize "good healthcare" and aspects of healthcare that matter most to patients by utilizing concept mapping (CM). Secondary objectives including an evaluation of the relative priorities of concept mapping domains among (1) various patient populations, including different demographic and clinical populations, and (2) patients and stakeholders (clinicians, researchers, purchasers, measure developers, health IT). Several major categories of good care were identified: (1) Doctor-Patient Communication, (2) Doctor characteristics and Behavior, (3) Appropriate Care, (4) Outcomes, (5) Patient as an Active and Informed Participant in Their Care, (6) Office Attributes, (7) Team Communication, and (8) Insurance Limitations.

McCaffrey S, Chiauzzi E, Chan C, Hoole M, Agarwal S, Paget L. (2017). Development of a Conceptual Framework of "Good Healthcare" from The Patient's Perspective ISPOR 22nd Annual International Meeting, Boston, MA USA, May 20-24, 2017 (Poster)

The Patient Voice Includes Emojis: A Case Study in the use of Probabilistic Topic Modeling to Characterize Patient Conversations in an Online Community of PTSD Patients

Presented: ISPOR 22nd Annual International Meeting
Primary Community: PTSD

To identify and respond to patient-defined priorities in care delivery and drug development, it is important to understand what is important to patients. Increasingly, patients share large volumes of free-text data over social media and within online communities. The text generated in these ways is often too massive to allow for complete human review and summarization, making approaches that use natural language processing particularly valuable. This case study demonstrated the use of probabilistic topic modeling, with attention to the preservation of emojis, to characterize free-text posts from post-traumatic stress disorder (PTSD) patients in the online patient community PatientsLikeMe (PLM). Based on analysis of 224,997 free-text posts contributed by 8,518 unique PTSD patients, fifty topics of conversation were identified, including topics related to quality of life (family, religion, music, literature, pets/service animals), exposure to trauma (military combat, abuse), symptoms (pain, depression, anxiety, insomnia, anger), and treatments (medical marijuana, supplements, side effects).

Eaneff S. (2017). The Patient Voice Includes Emojis: A Case Study in the use of Probabilistic Topic Modeling to Characterize Patient Conversations in an Online Community of PTSD Patients. ISPOR 22nd Annual International Meeting, Boston, MA USA, May 20-24, 2017 (Poster)

Multiple Sclerosis Patient Experiences with Access to Disease-modifying Therapies: A Qualitative Analysis on the Patient Impact of Medication Access Barriers

Presented: American Academy of Neurology Annual Conference 2017
Primary Community: Multiple sclerosis

For relapsing-remitting multiple sclerosis (MS) patients who are prescribed disease-modifying therapies (DMTs), adherence is critical to the effectiveness of the treatment. However, some patients in the United States (US) who are prescribed DMTs lack access to their medication. This study found that patients take a primary role in navigating a complex network of agents to overcome barriers to obtaining their DMT medication. Outcomes for patients could be improved, and overall costs and burden could be reduced, if policymakers, payers, and providers sought to better understand and minimize the impact of DMT access barriers on relapsing-remitting MS patients. This study presents a theoretical framework and preliminary data to support such efforts to improve patient quality of life (QoL) and clinical outcomes.

> Simacek K, Ko J, Varga S, Buechler N, Moreton D, and Katic B. (2017). Multiple sclerosis patient experiences with access to disease-modifying therapies: A qualitative analysis on the patient impact of medication access barriers. American Academy of Neurology Annual Conference, Boston, MA USA, April 25, 2017 (Poster)

2016

Methotrexate Adherence in an Online Network of Patients with Rheumatoid Arthritis

Presented: 2016 ACR/ARHP Annual Meeting
Primary Community: Rheumatoid arthritis

Methotrexate (MTX) is the most commonly prescribed disease-modifying antirheumatic drug (DMARD) in patients with rheumatoid arthritis (RA)and yet limited data are available regarding MTX-specific adherence. This study examined self-reported MTX adherence among RA patients in an online community. Patients were split into four groups based on whether they were taking MTX alone, in combination with biologic DMARDs, with non-biologic DMARDs, or with both. The group using MTX paired with biologic DMARDs had the lowest levels of adherence, as measured by the Moriskey Medication Adherence Scale (MMAS). MTX taken with a biologic DMARD was strongly predictive of moderate or low levels of MTX adherence compared with taking MTX alone.

> Katic B, Rodriguez AM, Curran C, Brethous M, Bernasconi C, Nebesky JM, Reiss W (2016) Methotrexate Adherence in Rheumatoid Arthritis. 2016 ACR/ARHP Annual Meeting, Washington, DC USA, November 11-16, 2016 (Poster)

How do migraines impact patient day-to-day life? An exploratory analysis of patient reported data from the PatientsLikeMe community

Presented: ISPOR 19th Annual European Congress, 2016
Primary Community: Migraine

This study's aim was to describe the experience of migraines as reported by patients from the PatientsLikeMe community, and to demonstrate how the lives of patients are affected by the frequency of migraine symptoms. Applied exploratory analysis and comparison of patient experience was performed

along several dimensions such as demographics, conditions/co-morbidities, symptoms, treatments, and quality of life (QoL) for migraine vs. headache cohorts and for chronic vs. episodic migraine cohorts. Results showed that migraine patients reported slightly more comorbidities than headache patients; chronic migraine patients reported anxiety more frequently than episodic patients; and higher migraine frequency was associated with worse QoL in terms of ability to be active, emotional experience, and life in general.

Naujoks C, Olson M, Simsek D, de Reydet de Vulpillieres F, Vo P, Kendall KR, Cerrato D (2016) How do migraines impact patient day-to-day life? An exploratory analysis of patient reported data from the PatientsLikeMe community. 2016 ISPOR 19th Annual European Congress, Vienna, Austria, October 29-November 2, 2016 (Poster)

Development and validation of the first measure of quality of life specific for patients with Mycosis Fungoides/Sezary

Presented: 3rd World Congress of Cutaneous Lymphomas (CLTF)
Primary Community: Mycosis fungoides/Sezary syndrome

Although patient quality of life (QoL) plays a key role in the management of Mycosis fungoides/Sézary syndrome (MF/SS), QoL is often estimated by administering generalized Patient Reported Outcome Measures (PROs), which are not disease-specific and may fail to capture the unique experiences of patients living with MF/SS. Additionally, some physicians administer more than one PRO, which increases respondent burden and may still not adequately quantify QoL for this population. The objective of this study was to design, develop and psychometrically evaluate the first health-related QoL instrument specifically for MF/SS patients. This instrument is free for clinicians, patients, and researchers, and the patient's voice was incorporated into each stage of measure development, which likely improved the relevancy and accuracy of this instrument in quantifying the patient's experience.

McCaffrey S, Black R, Sepassi M, Sharma G, Nagao M (2016) Development and validation of the first measure of quality of life specific for patients with Mycosis Fungoides/Sezary. 3rd World Congress of Cutaneous Lymphomas (CLTF), New York, NY, USA, October 26-28, 2016 (Poster)

Disease-modifying therapy access issues and their impact on multiple sclerosis patients: An online mixed methods study

Presented: AMCP NEXUS 2016
Primary Community: Multiple sclerosis

Access barriers to disease modifying therapies (DMTs) are a problem for multiple sclerosis (MS) patients in the United States. This mixed-methods study surveyed 507 people with relapsing remitting multiple sclerosis (RRMS) to describe the occurrence and types of DMT access difficulty and delays, and the impact of such barriers on patient outcomes. In addition, follow-up interviews were conducted with 10 participants

who experienced a relapse during access barriers to understand the process of obtaining a DMT. Results showed that DMT access difficulties occur frequently, particularly the need for authorizing documentation, high out-of-pocket costs, and agency/provider coordination problems. Patients often serve as their own agents when navigating DMT access difficulties and obtaining MS medication, but they may receive help from their doctor/doctor's staff. Access barriers to DMT medications impact MS patients physically (relapses and stress) and financially (high costs). This worsens medication adherence and quality of life. Actual DMT access patterns may be quite complex; they involve multiple agents with the patient playing the primary coordinating role.

Ko J, Katic B, Simacek K, Moreton D, Buechler N, Varga S (2016) Disease-Modifying Therapy Access Issues and Their Impact on Multiple Sclerosis Patients: An Online Mixed Methods Study. 2016 AMCP NEXUS, National Harbor MD, October 3-6, 2016 (Poster)

Measuring Free-Living Ambulation in Multiple Sclerosis using Consumer-Grade Activity Tracker

Presented: Basel Life Science Week 2016
Primary Community: Multiple sclerosis

Due to the difficulty involved in collecting data on wearable sensors, little information exists regarding how patients with chronic medical conditions use this technology over time. This study used the PatientsLikeMe online platform to engage 203 patients in data tracking and sharing with Fitbit One activity trackers. The program demonstrated short-term success in its ability to assess activity patterns and their relation to disability severity; however, long-term data collection remains challenging in the absence of continual patient outreach and support. Although challenges accompany long-term data collection using wearable sensors, this study demonstrates the potential for wearable sensor programs to automatically monitor functional changes and medical events, and to possibly support clinical decision-making.

DasMahapatra P, Eaneff S, Chiauzzi E, Wicks P. (2016). Measuring free-living ambulation in multiple sclerosis patients using a consumer-grade activity tracker. Basel Life Science Week, Basel, Switzerland, September 19-23, 2016 (Poster)

The Experience of Weight Loss and its Associated Burden in Patients with Non-Small Cell Lung Cancer: Results of an Online Survey

Presented: Palliative Care in Oncology, 2016
Primary Community: Non-small cell lung cancer

Patients living with non-small cell lung cancer (NSCLC) sometimes experience considerable weight loss. While the health consequences related to unintended weight loss are serious and negatively impact quality of life and prognosis, gaps exist in how unintentional weight loss is assessed, identified and treated

clinically. This comparison of self-reported disease burden and quality of life in people with advanced NSCLC who lost considerable weight and those who did not, supported that weight loss negatively affects patients' quality of life and is associated with more distress and symptoms, particularly fatigue and appetite loss. Weight-loss-related symptoms also significantly impact people's lives. Interventions targeted at maintaining/increasing body weight are needed and may help to improve well-being and reduce key symptoms in advanced NSCLC patients with considerable weight loss.

Rodriguez AM, Braverman J, Aggarwal D, Friend J, Duus E (2016) The Experience of Weight Loss and its Associated Burden in Patients with Non-Small Cell Lung Cancer: Results of an Online Survey. 2016 Palliative Care in Oncology, San Francisco, CA USA, September 9-10, 2016 (Poster)

Conjoint Analysis of Preferred Features of a Hypothetical First Dose Observation Program Among Patients and Neurologists before Fingolimod Initiation in Multiple Sclerosis

Presented: CMSC Annual Meeting, National Harbor 2016
Primary Community: Multiple sclerosis

Given the potential for adverse events on treatment initiation with fingolimod, a disease-modifying therapy, first dose observation (FDO) programs are conducted. FDO programs can be implemented in various ways, and this survey was administered to 254 patients and 225 neurologists to examine program attributes that matter most to these populations. Preferences among patients and neurologists increased factors including number of locations in which to conduct FDO, familiarity and competence of medical team, and automation of administrative tasks. The choice and convenience of FDO programs ranked most important among patients and neurologists, which can guide the implementation of new and existing programs in the future.

Fox E, Ko J, Wicks P, Park Y, DasMahapatra P, Kendall K, Hong W, Burton E, Hawker K, Kosoy I, Liakhovitski D, Herrera V (2016) Conjoint Analysis of Preferred Features of a Hypothetical First Dose Observation Program Among Patients and Neurologists before Fingolimod Initiation in Multiple Sclerosis. 2016 CMSC Annual Meeting, National Harbor, MD, June 1-4, 2016 (Poster)

First-Line Treatment Preference in Relapsing-Remitting Multiple Sclerosis: An Online Choice Study in Patients and Physicians

Presented: CMSC Annual Meeting 2016
Primary Community: Multiple sclerosis

Disease-modifying treatments (DMTs) approved for the treatment of relapsing-remitting multiple sclerosis (RRMS) vary on factors including efficacy, safety, tolerability, method of administration, and cost. Whereas

physicians are more concerned about risk of side effects than are patients, both groups agree that efficacy takes highest priority in treatment decision-making. Despite the fact that both patients and physicians prefer efficacy when considering DMTs, real world practice does not reflect this preference. These results suggest that RRMS treatment might be improved with a higher degree of system-wide communication about medication preferences.

Fox E, Ko J, Wicks P, Yujin P, DasMahapatra P, Kendall K, Hong W, Burton E, Hawker K, Kosoy I, Liakhovitski D, Herrera V. (2016). First-Line Treatment Preference in Relapsing-Remitting Multiple Sclerosis: An Online Choice Study in Patients and Physicians. 2016 CMSC Annual Meeting, National Harbor, MD, June 1-4, 2016 (Poster)

Evaluation of Psychometric Properties of European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 15 Palliative (EORTC QLQ-C15-PAL) in Multiple Myeloma Patients

Presented: 2016 European Hematology Association Congress
Primary Community: Multiple myeloma

There is a paucity of literature examining the health-related quality of life (HRQoL) in patients with multiple myeloma (MM) at different treatment stages in a real-world setting. The EORTC QLQ-C15-PAL was developed by shortening the EORTC QLQ-C30 from 30 to 15 items for easier administration to patients receiving palliative care. The performance of the QLQ-C15-PAL in measuring HRQoL in relation to its parent version (QLQ-C30) in patients with MM was evaluated for the first time in this study. The results showed that the psychometric properties of the QLQ-C15-PAL were comparable to the longer version, QLQ-C30. Further study, with a larger sample size of multiple myeloma patients, would be useful for assessing the internal consistency of the physical functioning domain of the QLQ-C15-PAL.

Hu XH, Rodriguez AM, Katic B, Purnomo L, Gibson C (2016). Evaluation of Psychometric Properties of European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 15 Palliative (EORTC QLQ-C15-PAL) in Multiple Myeloma Patients. 21st Annual European Hematology Association Congress, Copenhagen, Denmark, June 9-12, 2016 (Poster)

Health-related Quality of Life in Patients With Multiple Myeloma in Relation to Line of Treatment and Response

Presented: 2016 European Hematology Association Congress
Primary Community: Multiple myeloma

Health-related quality of life (HRQoL) in patients with multiple myeloma (MM) has mostly been evaluated in controlled trials composed of homogeneous patient populations. This study's goal was to document and compare self-reported HRQoL in patients with multiple myeloma across different treatment stages (for

example receiving their first line of treatment, or second, or third) and across response statuses (for example, complete remission, partial remission, or relapsed/progressed disease). Results showed that, in a real-world setting, scores for HRQoL, physical functioning, social functioning, and pain were more closely tied to current response status than to how many times the patient had previously switched treatments.

> Hu HX, Katic BJ, Lowe M, Purnomo L, Gibson C, Rodriguez AM (2016) Health-related Quality of Life in Patients with Multiple Myeloma in Relation to Line of Treatment and Response. 21st Annual European Hematology Association Congress, Copenhagen, Denmark, June 9-12, 2016 (Poster)

Factors Affecting the Attitudes of Patients with Systemic Lupus Erythematosus Regarding Potential Clinical Trial Participation

Presented: EULAR 2016
Primary Community: Systemic lupus erythematosus

Systematic lupus erythematosus (SLE) is an autoimmune disorder affecting skin, joints, kidneys, brain, and other organs. Recruiting participants for SLE clinical trials may be challenging for several reasons, including patients' concerns that medications may exacerbate their condition or cause side effects. This study explored how real-world patient experiences collected on the PatientsLikeMe platform can help inform efforts to design and execute patient-centric clinical trials. Results showed that the greatest impact of SLE on patients' lives was primarily related to fatigue and/or pain. Sixty percent of patients indicated that their disease affected their ability to work. Many reported being unaware of clinical trial options. While SLE patients had concerns about possible downsides of participating in clinical trials (side effects, worsening health, and treatment with placebo), they cited factors that could make them more willing to participate.

> McNaughton E, Braverman J, Lops S, Felicione E, Wagner C (2016) Factors Affecting the Attitudes of Patients with Systemic Lupus Erythematosus Regarding Potential Clinical Trial Participation. 2016 EULAR, London, UK, June 8-11, 2016 (Poster)

SLE Flares from the Patient Perspective: What Patients Discuss in an Internet Forum

Presented: ISPOR 2016
Primary Community: Systemic lupus erythematosus

Systemic lupus erythematosus (SLE) is a multi-system inflammatory autoimmune disease influenced by a variety of factors, with diverse clinical manifestations affecting multiple organ systems and variable long-term outcomes for patients. Some studies report that flares in disease activity contribute to poor health-related quality of life (HRQoL) in patients with SLE. Information on the diversity of lupus symptoms and the symptom experience during flares is based primarily on clinical assessment rather than on patient reports. This study identified key aspects of the SLE flare experience as described by patients in their own words. Directed content analysis of forum posts mentioning flares by patients self-reporting an SLE

diagnosis found that current clinical assessments do not completely align with patient perceptions of SLE flares. Future research should seek to reconcile these differences.

Shiozawa A, Katic B, Simacek K, Curran C, Merikle E (2016) SLE Flares from the Patient Perspective: What patients discuss in an internet forum. 2016 ISPOR, Washington, D.C., USA, May 21-25, 2016 (Poster)

Treatment Preference in Relapsing-Remitting Multiple Sclerosis: An Online Choice Study in Patients and Neurologists

Presented: American Academy of Neurology 2016
Primary Community: Multiple Sclerosis

Patients and neurologists each consider numerous factors when choosing among the various disease modifying treatments for relapsing-remitting multiple sclerosis. This survey of 298 patients and 225 neurologists revealed that these two groups are highly concerned about treatment efficacy when choosing among and switching between DMTs, and that patients are concerned about side effects to a lesser degree than are neurologists. Both groups view parenteral drug administration as the least preferable among the various treatment factors. These results suggest that treatment efficacy is of central importance to both patients and neurologists, with slowing disease progression ranking most important, followed by decreasing frequency of relapses and preventing new MRI lesions.

Ko J, Fox E, Wicks P, DasMahapatra P, Kendall K, Hong W, Burton E, Hawker K, Kosoy I, Liakhovistski D, Park J, Herrera V (2016) Treatment Preference in Relapsing-Remitting Multiple Sclerosis: An Online Choice Study in Patients and Neurologists. Neurology. April 5, 2016.

2015

Patient Insights and Voice on Major Depressive Disorder Treatment Efficacy and Symptom Perception (PIVOT) Study: Initial Findings from the PatientsLikeMe Online Community

Presented: National Network of Depression Centers (NNDC) Annual Conference 2015
Primary Community: Major Depressive Disorder (MDD)

PatientsLikeMe collected data from 17,166 members reporting MDD to better understand the connection between the perceived effectiveness of their medication and the severity of MDD symptoms focusing on concentration problems. The effectiveness of medication was inversely related to all evaluated MDD symptoms and was most strongly correlated with the severity of anhedonia (the inability to feel pleasure), depressed mood, and low self-esteem. Most patients (80%) reported some concentration impairment even when reporting none or mild depressed mood, highlighting an unmet need for treating cognitive symptoms in depression.

Drahos J, Cerrato D, Sherman J, Wang V, Bradley M, Mack S, Sarkey S, Chiauzzi E, Tomori D (2015) Patient Insights and Voice on Major Depressive Disorder Treatment Efficacy and Symptom Perception (PIVOT) Study: Initial Findings from the PatientsLikeMe Online Community. NNDC 2015 Annual Conference, National Network of Depression Centers (NNDC), Nov 4-6, 2015 (Poster)

Development of a Patient- Centric PRO Instrument to Assess the QoL of Patients with Mycosis Fungoides/ Sézary Syndrome- Type Cutaneous T-Cell Lymphoma (MF/SS-CTCL)

Presented: International Society for Quality-of-Life Research (ISOQOL) 2015
Primary Community: MF/SS-CTCL

In collaboration with Actelion Pharmaceuticals Ltd., PatientsLikeMe (PLM) developed the Cutaneous T-Cell Lymphoma-Quality of Life (CTCL-QOL) instrument, a patient-centric patient reported outcome (PRO) measure, to understand the key areas of impact of mycosis fungoides/Sézary syndrome-type cutaneous T-cell lymphoma (MF/SS-CTCL) on patients' quality of life. The instrument was developed through a 4-step process that contained: literature review, interviews and computer-based survey with MF/SS-CTCL patients, qualitative and quantitative analysis of patients' feedback on the preliminary items, and psychometric evaluation of the final instrument. The final 13-item CTCL-QOL proved to be a reliable and valid instrument for assessment of patients' experience living with MF/SS-CTCL.

Braverman J, Towner A, Raja P, Harrington M, Nagao M, Sepassi M (2015) Development of a Patient-Centric PRO Instrument to Assess the QoL of Patients with Mycosis Fungoides/ Sézary Syndrome-Type Cutaneous T-cell Lymphoma (MF/SS-CTCL). Oct 22, 2015

Treatment Satisfaction and Side Effect Experience with Fingolimod and Dimethyl Fumarate for Multiple Sclerosis: Findings from an Online Patient Cohort

Presented: European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS) 2015
Primary Community: Multiple Sclerosis (MS)

Whereas patients with MS once were dependent on needle-based therapies to treat their disease, today there is a range of oral medication options available to them such as fingolimod (Gilenya) and dimethyl fumarate (Tecfidera). In this survey of nearly 300 patients with MS living in the US who had taken either of

these treatments, we sought to identify treatment history, levels of treatment satisfaction, and side effects, as well as differences in profile between the two treatments.

> Sasane R, Rasouliyan L, Katic B, Wicks P, Nazareth T, Flood E, Jo JJ, Johnson K, Herrera V (2015) Treatment Satisfaction and Side Effect Experience with Fingolimod and Dimethyl Fumarate for Multiple Sclerosis: Findings from an Online Patient Cohort. ECTRIMS Online Library. Oct 9, 2015; 116055

Relationships Among Treatment Decision-Making, Multiple Sclerosis-Related Symptoms and Disease Severity: Findings from a US Web- Based Patient Preference Survey

Presented: European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS) 2015
Primary Community: Multiple Sclerosis (MS)

Increasingly, patients with MS are invited to learn more about their treatment options and participate in shared decision-making with their healthcare provider. In this survey of nearly 1,000 patients living with MS in the US, we not only identified that most patients would prefer to make treatment decisions jointly with their doctor but also found stronger preferences for patient decision-making in patients who chose not to take a therapy or who were seeing a general physician rather than a neurologist or MS specialist.

> Wicks P, Thomas NP, Kotowsky N, Cochin E, Hurley D, Musch B, Julian L (2015) Relationships Among Treatment Decision-Making, Multiple Sclerosis-Related Symptoms and Disease Severity: Findings from a US Web-Based Patient Preference Survey. ECTRIMS Online Library. Oct 8, 2015; 115106

US Patient Perspectives on Multiple Sclerosis Treatment Experience: Results of a US Web-Based Survey

Presented: European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS) 2015
Primary Community: Multiple Sclerosis (MS)

Patients living with MS now face a range of over a dozen disease modifying therapy (DMT) options to reduce the frequency of their relapses and modulate their outcomes. In this survey of nearly 1,000 patients living with MS, we identified the major reasons why some patients choose not to take a DMT. For those that do, we sought to understand what drives treatment satisfaction and switching between different DMTs in patients with both relapsing-remitting and secondary progressive forms of the disease.

> Wicks P, Thomas NP, Kotowsky N, Cochin E, Musch B, Julian L (2015) US Patient Perspectives on the Multiple Sclerosis Treatment Experience: Results of a US Web-Based Survey. ECTRIMS Online Library. Oct 8, 2015; 115368

Suicide Ideation and Behavior Assessment Tool (SIBAT): A Novel Measure of Suicidal Ideation and Behavior and Perceived Suicide Risk

Presented: ICSR 2015, ISCTM 2015, IASR/AFSP 2015
Primary Community: Mood Disorders

Accurately diagnosing and assessing the risk of suicide in patients is critical for clinicians in a variety of situations including the emergency room. Existing tools to assess suicidal ideation and behavior omit a number of risk factors and do a poor job of distinguishing relatively static lifelong risk factors from more recent and highly dynamic life events. A new instrument, the SIBAT, was developed to address these limitations and included a program of psychometric testing and validation using a sample of 700 patients from PatientsLikeMe.

Alphs L, Canuso C, Williamson D, and the SIBAT Consortium (2015) Suicide Ideation and Behavior Assessment Tool (SIBAT): A Novel Measure of Suicidal Ideation and Behavior and Perceived Suicide Risk. Schizophrenia Bulletin (2015) 41 (suppl 1): S1-S341

Understanding Preferences for Type 2 Diabetes Mellitus Self-Management Support – a Patient- Centered Approach

Presented: American Diabetes Association (ADA) 2015
Primary Community: Type 2 Diabetes

The participation rate of type 2 diabetes mellitus (T2DM) patients in self-management support programs remains low. Since little is known about the perspectives and preferences of T2DM patients regarding these programs, PatientsLikeMe encouraged patients with T2DM in the US to share their diabetes goals as well as their preferences for T2DM self-management support programs through an online survey. Although the majority of patients (65%) out of the 294 patients who responded to the survey were not participating in any program, most patients had goals of improving their diet, losing weight, and achieving stable blood glucose levels. The most preferred type of support among patients was diet/weight loss support (62%), and most patients preferred to receive support from doctors or nurses (61%) and dietitians (55%). Incorporating patient preferences for support types and formats into the design of these programs may offer one method of engaging T2DM patients more effectively.

Lopez J, Katic B, Fitz-Randolph M, Jackson R, Chow W, Mullins C (2015) Understanding Preferences for Type 2 Diabetes Mellitus Self-Management Support- a Patient-Centered Approach. ADA 2015, 75th Anniversary Scientific Sessions of the American Diabetes Association, Boston, June 5-9, 2015 (Poster)

Patients' Experiences with Mycosis Fungoides and Sézary Syndrome-Cutaneous T-Cell Lymphoma (MF/SS-CTCL): Evidence from Qualitative Research of a Patient Reported Outcome Measure Developed on an Online Research Platform

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR) 2015
Primary Community: MF/SS-CTCL

This study presents the initial stage of development of the Cutaneous T-Cell Lymphoma-Quality of Life (CTCL-QOL) instrument through PatientsLikeMe's Open Research Exchange (ORE). ORE is particularly useful for developing patient reported outcome measures (PROM) for rare conditions such as MF/SS-CTCL, in which the recruitment process is particularly challenging. This process presents improvement in time, cost, and overall efficiency while maintaining scientific rigor and quality.

> Towner A, Raja P, Braverman J, Harrington M, Simacek K, Nagao M, Sepassi M (2015) Patients' Experiences with Mycosis Fungoides and Sézary Syndrome–Cutaneous T-Cell Lymphoma (MF/SS-CTCL): Evidence from Qualitative Research of a Patient Reported Outcome (PRO) Measure Developed on an Online Research Platform. Value in Health, 18(3): A25

Unmet Needs and Treatment Patterns in Lupus: Results from an Online Community

Presented: International Society for Pharmacoeconomics and Outcomes Research (ISPOR) 2015
Primary Community: Lupus

People living with lupus often have their disease measured through a variety of clinician-assessed measures such as their levels of organ function or rash. Using a survey from an online community, PatientsLikeMe identified high levels of moderate or severe pain, fatigue, brain fog, and insomnia that may go unrecorded. Free text forum discussions were also analyzed to learn more about what terms co-occur with discussions about pain, finding that pain frequently occurs outside the context of a flare and is a major issue for patients.

> Wang VC, Hanger M, Vaughan T, Woyczynski M, Wicks P (2015) Unmet Needs and Treatment Patterns in Lupus: Results from an Online Community. Value in Health, 18(3): A299

A Novel Tool for Monitoring Patient Experiences with Nintedanib and Pirfenidone in Idiopathic Pulmonary Fibrosis: Preliminary Data and Insights

Presented: American Thoracic Society (ATS) 2015
Primary Community: Idiopathic Pulmonary Fibrosis (IPF)

In 2014, Pirfenidone and Nintedanib became the first two medications to win approval from the Food and Drug Administration for delaying the progression of idiopathic pulmonary fibrosis (IPF). PLM sought to

understand how patients with IPF become aware of new treatment options, which factors influence the treatment decision-making process, and if there are differences between how patients experience side effects in the real-world setting versus clinical trials. Of the 757 patients with idiopathic pulmonary fibrosis who responded, the majority (72%) reported not taking a treatment, and 38% of these patients were unaware of new options for treatment. Decreased appetite, indigestion, and vomiting were reported more frequently (10%) as side effects among the 23% of patients who reported taking Pirfenidone, while abdominal pain and diarrhea were more frequently experienced by the 6% of patients who reported taking Nintedanib. The rate of side effects to the medications experienced by patients differed from that observed in clinical trials.

Blaser D, Wang V, Wicks P (2015) A Novel Tool for Monitoring Patient Experiences with Nintedanib and Pirfenidone in Idiopathic Pulmonary Fibrosis: Preliminary Data and Insights. ATS 2015, 111th Int. Conf. of the American Thoracic Society (ATS), May 15-20, 2015 (Poster)

Remote Tracking of Walking Activity in MS Patients in a Real-World Setting

Presented: American Academy of Neurology (AAN) 2015
Primary Community: Multiple Sclerosis (MS)

Measuring disability in multiple sclerosis is challenging in both clinical and research settings, requiring trained professionals or specialized equipment. Widely available consumer devices known as “wearables” can be worn on the wrist, foot, or clothing, and provide continuous passive data on walking activity, which is frequently impaired in MS. In this study, almost 250 patients with MS were recruited within just 24 hours and provided with a FitBit activity band as well as surveys on their levels of function and comfort using the device.

McInnch JD, Datta S, DasMahapatra P, Chiauzzi E, Bhalero R, Spector A, Goldstein S, Morgan L, Relton J (2015) Remote Tracking of Walking Activity in MS Patients in a Real-World Setting. Neurology 84(14 supplement): P3.209

The POEM Study: Patient Usage and Satisfaction with an Online Health Management Platform for Epilepsy

Presented: American Academy of Neurology (AAN) 2015
Primary Community: Epilepsy

In this further exploration of the POEM study, we sought to investigate how often veterans with epilepsy used PatientsLikeMe and their overall levels of satisfaction with the site. Those who completed the study logged in about once a week, about a third sent a private message to another patient, and about 15% posted in the forum. Overall, satisfaction was high among study completers.

Hixson J, Barnes D, Parko K, Durgin T, Graham A, Van Bebber S, Wicks P (2015) User Retention and Utilization of an Online Digital Health Platform for Epilepsy. Neurology 84(14 Supplement): P7.031

How Common Are “ALS Reversals?”

Presented: American Academy of Neurology (AAN) 2015
Primary Community: Amyotrophic Lateral Sclerosis (ALS)

While ALS is normally thought of as a progressive illness, anecdotal reports and clinical experience show that patients may sometimes experience transient “plateaus” or even “reversals” in their progression. In this collaboration with Duke and MGH, we explored how often these happened, investigating data from the PRO-ACT clinical trial database. We identified that while reversals and plateaus were relatively common, they were almost always transient.

Bedlack R, Vaughan T, Heywood J, Wicks P (2015) P4.131 How Common Are "ALS Reversals”? Neurology 84(14 Supplement): P4.131

2014

Preferred Characteristics of Oral Multiple Sclerosis Treatments and Predicted Adherence: An Online Discrete Choice Experiment

Presented: AMCP 2014 Nexus
Primary Community: Multiple Sclerosis

Oral disease-modifying therapies (DMTs) occupy a unique niche in terms of ability to delay rate of MS progression, reduce frequency of relapses, alter lesion burden on MRI imaging, and contribute to side effects and adverse events. With the new class of oral treatments entering the market, patients and clinicians must make increasingly complex tradeoffs in choosing an appropriate DMT. This study performed a conjoint analysis to learn how attributes of oral disease-modifying treatments (DMTs) for multiple sclerosis impacted patient preference and predicted non-adherence among patients who had not previously taken an oral DMT for MS. Results showed that patients seek a balance between efficacy, safety, tolerability, adherence, potential need for monitoring, and cost effectiveness when choosing from among oral treatment options.

Wicks P, Bandes D, Park J, Liakhovitski D, Koudinova T, Sasane R (2014) Preferred Characteristics of Oral Multiple Sclerosis Treatments and Predicted Adherence: An Online Discrete Choice Experiment. 2014 AMCP Nexus, Boston, MA USA, October 7-10, 2014 (Poster)

Patient Perspectives on Primary Palliative Care

Presented: Center to Advance Palliative Care (CAPC) National Seminar 2014
Primary Community: Various

In collaboration with a group at the American Board of Internal Medicine (ABIM), PatientsLikeMe developed a new questionnaire as part of the Palliative Care for Primary Care & Subspecialist Physicians PIM Practice Improvement Module® using the PatientsLikeMe Open Research Exchange platform. Through the partnership, the group was able to quickly recruit over 1,300 patients who provided feedback on the items and helped to provide psychometric data for its validation.

Baranowski R, Arnold G, Lynn L, Harrington M (2014) Patient Perspectives on Primary Palliative Care. Journal of Palliative Medicine 18(4): A-1-A-33

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 in both outcomes. This pragmatic study demonstrates the potential impact of digital health solutions on epilepsy.

Hixson J, Wicks P, Barnes D, Parko K, Durgin T, Van Bebber S, Graham A (2014) The POEM Study: Testing the Impact of a Digital Health Platform in U.S. Veterans with Epilepsy. Neurology 83(2): E38

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 A1C 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 (PPRN). 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.

Okun S, Wicks P, Scott M, Gilbert J (2014) Patient-Informed Clinical Trials: Cross-Sectional Survey on a Patient Powered Research Network, PatientsLikeMe. Drug Information Association, 2014

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

Presented: American Thoracic Society International Conference (ATS) 2014
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.

Blaser D, DasMahapatra P (2014) Characteristics of an online, patient-powered research network of idiopathic pulmonary fibrosis patients. American Thoracic Society International Conference, 2014

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.

> Harrington M, Heywood B, Rura S, Wicks P (2014) An open research exchange for online patient feedback in PRO development. Value in Health, 17(3):A197

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.

> McCarrier K, Bull S, Simacek K, Wicks P, Pierson R, Wolfe M, Cella D, Rothman M (2014). Online social networks-based qualitative research to identify patient-relevant concepts in chronic lymphocytic leukemia. Value in Health, 17(3):A196

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.

> Blaser D, Katic B, Wicks P (2013) Sleep problems and quality of life in patients with idiopathic pulmonary fibrosis. Pulmonary Fibrosis Summit, 2013.

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 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.

> Wicks P, Heywood B, Heywood J. Online platform to accelerate patient involvement in open instrument development. Quality of Life Research, 22(1), 2013, p. 55

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.

Borghs S, De La Loge C, Dimova S, Durgin T, Phillips G, Mueller K, LaFosse C, Wicks P (2013) PatientsLikeMe Epilepsy Community: Factors Affecting Quality of Life. Neurology, 80 (Meeting Abstracts 1): P03.122

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
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.

Merikle E, Gilligan A, Espay A, Wicks P (2013) PatientsLikeMe Parkinson's Disease Community: Assessing the Impact of Self-reported Disease Stage and Symptom Burden on Falls in Members of an Online Parkinson's Disease Community. Movement Disorders; 28 Suppl 1: P253

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
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.

Merikle E, Gilligan A, Espay A, Wicks P (2013) 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. Movement Disorders; 28 Suppl 1: P254

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.

> Dimova S, de la Loge C, Durgin T, Mueller K, Lafosse C, Massagli MP, Wicks P (2012) Characteristics of Users of the Epilepsy Community PatientsLikeMe.com: An update. Neurology, 78:P01.062

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 (MS)
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.

> Bove R, Secor E, Vaughan TE, Wicks P, Glanz B, Weiner H, Chitnis T, de Jager PL (2012) Comparison of Demographic and Disease Characteristics in Patients with Multiple Sclerosis at an MS Clinic and on an Online Research Forum. Neurology, 78 (Meeting Abstracts 1): P01.145

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 (MS)
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.

Bove R, Secor E, Vaughan TE, Chitnis T, Wicks P, de Jager PL (2012) Relationship between body mass index and disease severity in an online multiple sclerosis population. Multiple Sclerosis, 18: 55-227

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.

Banerjee AK, Ingate S, Mayall S, Okun S, Clifford D, Wicks P, Heywood J (2012) Patient Reported Outcomes (PRO) are Key to Post Launch Safety and Risk Management. Pharmacoepidemiology and Drug Safety, 21(S3):213-214

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 (ALS)
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.

Wicks P, White L A. (2012) Illness Burden in Patients with ALS and Their Caregivers: A Web-Based Survey. Amyotrophic Lateral Sclerosis 13(S1):135-153

2011

Patient-reported Clinician Adherence to Epilepsy Performance Measures of Quality Care

Presented: American Academy of Neurology (AAN) 2011
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 specialties 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.

Wicks P, Fountain N (2011) Patient-reported clinician adherence to Epilepsy Performance Measures of quality care. Neurology, 76(9)Suppl 4:A49

PatientsLikeMe, a Data-Sharing Online Community: Benefits for Patients with Epilepsy

Presented: American Academy of Neurology (AAN) 2011
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 of 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.

De la Loge C, Massagli MP, Wicks P (2011) PatientsLikeMe, a Data-Sharing Online Community: Benefits for Patients with Epilepsy. Neurology, 76(9)Suppl 4:A116-117

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

Presented: American Academy of Neurology (AAN) 2011
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).

De la Loge C, Keininger D, Isojarvi JI, Massagli MP, Wicks P (2011) Characteristics of Users of the Epilepsy Community PatientsLikeMe.com and Comparison with a Representative Claims Database. Neurology, 76(9)Suppl4:A54-55

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.

De la Loge C, Dimova S, Phillips G, Mueller K, Lafosse C, Wicks P (2011) PatientsLikeMe Epilepsy Community: An Insight into Symptoms and Side Effects Reported Online by Patients with Epilepsy. Epilepsia 52(Suppl. 6):147-148

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, age 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.

De la Loge C, Dimova S, Massagli MP, Wicks P (2011) The PatientsLikeMe Epilepsy Community: A Unique Insight into the Lives of Patients with Epilepsy. Value in Health, 14(3):A209-210

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) in comparison 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-remitting 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 (MRSR-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 endpoint 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 the Global Impression Scale; thus, it is a valid assessment of bulbar function in ALS patients.

Smith RA, Wicks P, Yagi N, Thisted RA (2011) Development of a Self-Report Bulbar Function Scale (CNS-BFS). Neurology, 76(9)Suppl4:A48-49

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 regimens.

Wicks P, Massagli MP, Kulkarni AS, Dastani H (2011) Development of the MS-Treatment Adherence Questionnaire (MS-TAQ): A Scale to Measure Barriers to Adherence in Multiple Sclerosis. Neurology, 76(9)Suppl4:A478

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.

> Turner M, Wicks P, Brownstein C, Massagli M, Toronjo M, Talbot K, Al-Chalabi A (2010) P181 Limb Dominance and Laterality of Onset In ALS: A Pathogenic Role for Exercise or Clue to a Cortical Vulnerability? Amyotrophic Lateral Sclerosis, 11(S1):150-8

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 regimens 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 (2010) 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.

> Brownstein C, Wicks P, Vaughan T, Massagli M, Junge G (2010) F-PO2021 Characteristics of an Online Renal Data-Sharing Initiative – The PatientsLikeMe Transplants Community. Journal of the American Society of Nephrology, 21, 547A

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, age 20-50 years, receiving polytherapy, and receiving newer AEDs.

> de la Loge C, Keininger D, Isojarvi J, Massagli M, Wicks P (2010) Characteristics of users of the Epilepsy community of PatientsLikeMe.com and comparison with a representative claims database. Epilepsia Online Supplement, Abstract 1.305

2009

Pseudobulbar Affect: Better Understanding Through Research on a Social Network

Presented: ALS/MND Symposium 2009
Primary Community: Amyotrophic Lateral Sclerosis (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 effect: 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: ALS/MND Symposium 2009
Primary Community: Amyotrophic Lateral Sclerosis (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 regard 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 disease progression. Thus a system that rewards genetic data with better predictive ability may drive demand for genetic testing.

Brownstein C, Vaughan T, Heywood J, Wicks P (2009) An internet-based approach to genetic discovery in ALS. Amyotrophic Lateral Sclerosis, 10(5):122

Internet-based observational study finds no impact of lithium on ALSFRS-R progression

Presented: ALS/MND Symposium 2009
Primary Community: Amyotrophic Lateral Sclerosis (ALS)

A small clinical trial had reported that lithium carbonate delayed the progression of ALS, prompting many patients to begin taking lithium. We present the 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.)

Wicks P, Vaughan T, Massagli M, Heywood J (2009) Internet-based observational study finds no impact of lithium on ALSFRS-R progression. Amyotrophic Lateral Sclerosis (2009).

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%).

> Wicks P, MacPhee GJA (2008) Pathological gambling and hobbyism amongst internet users: Comparison of Parkinson's disease and ALS/MND. Movement Disorders, 23:S1, S285

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.

Wicks P, Frost J, Massagli MP, Heywood J (2008) Online data-sharing community for patients with Parkinson's disease: PatientsLikeMe.com. Movement Disorders, 23:S1, S331

A Patient-led Trial of Lithium in ALS Using the Internet

Presented: ALS/MND International Symposium 2008
Primary Community: Amyotrophic Lateral Sclerosis (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.

Wicks P, Massagli M, Frost J, Macedo H, Felzer K, Heywood J (2008) A patient-led trial of lithium in ALS using the internet. Amyotrophic Lateral Sclerosis, 9(S1):59

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.

Wicks P (2007) Telesocial medicine for neurological disorders: PatientsLikeMe.com. Journal of Neurology, Neurosurgery & Psychiatry, 78(7):785-786