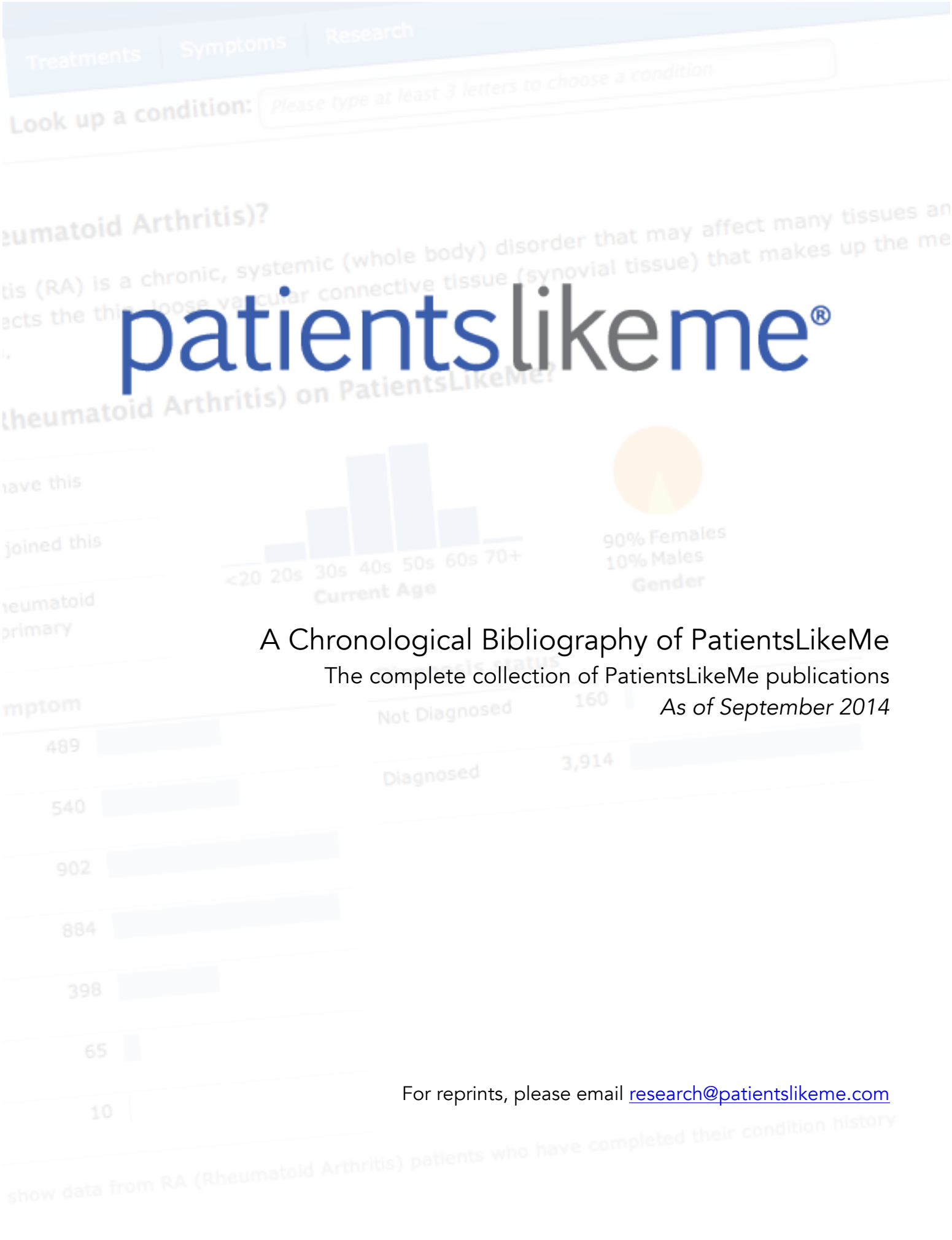

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2014

Adaptation and validation of the Treatment Burden Questionnaire (TBQ) in English using an Internet platform

Primary community: General Collaborator: Paris Descartes University

The Open Research Exchange (ORE) is a unique platform that allows researchers to rapidly develop and validate patient reported outcome measures (PROs) through concept elicitation, psychometric validation, reliability testing, test-retest, and analysis of changes over time. In the first output of this Robert Wood Johnson Foundation-funded study, an international team of health researchers was able to translate and validate a new measure of treatment burden in a global sample of over 600 patients in just two months.

Tran V, Harrington M, Montori VM, Barnes C, Wicks P, Ravaud P (2014) Adaptation and validation of the Treatment Burden Questionnaire (TBQ) in English using an internet platform, BMC Medicine, 12(1):109

Patients leading the direction of clinical research

Primary community: General Collaborator: N/A

Patients are increasingly becoming engaged in research, whether as citizen scientists, research partners in the development of studies, or as engaged participants in clinical trials. In this transcript and video Q&A, VP of Innovation Paul Wicks outlines the new era of participant-led research including the potential ethical issues, scientific challenges to be overcome, and innovative new platforms such as the Open Research Exchange.

Wicks P (2014) Questions and Answer: Patients leading the direction of clinical research – an interview with Paul Wicks, BMC Medicine, 12:118

Could digital patient communities be the launch pad for patient-centric trial design?

Primary community: General Collaborator: N/A

The system of medical discovery does not revolve around patients as unique individuals with preferences, needs, and desires. Rather it revolves around scientific scrutiny, the needs of the sponsor, and the desires for regulatory approval. The patient is only a subject. Is it any wonder, then, that some patients have rejected the current medical paradigm and sought to find their own path? This editorial highlights the potential of patient powered research networks to close the gap between trial designers and patients.

Wicks P (2014) Could digital patient communities be the launch pad for patient-centric trial design? Trials, 15:172

Patient-Centeredness in the Design of Clinical Trials

Primary community: General Collaborator: University of Maryland

There is growing concern that recruitment and retention of patients in clinical trials is becoming increasingly challenging. Without reliable trials, the development of new treatments and improved outcomes for patients risks being delayed significantly. We propose that certain innovative trial designs such as pragmatic trials, adaptive trials, and the use of Bayesian statistics in trials might provide more appealing trial designs than the traditional experimental double-blind randomized placebo-controlled trial.

Vandigo J, Mullins D, Zheng Z, Wicks P (2014) Patient-centeredness in the design of clinical trials, Value in Health, Online ahead of print May 5th

Stakeholder Engagement in Patient Centered Research: High Touch or High Tech?

Primary community: General Collaborator: N/A

While digital technology becomes widespread and offers exciting opportunities to accelerate research, it is worth remembering that traditional research methods still have a number of benefits. In this Expert Review of Pharmacoeconomics & Outcomes Research, discussants Danielle Lavallee (University of Washington), Paul Wicks (PatientsLikeMe), Rafael Cristancho (University of Washington) and Daniel Mullins (University of Maryland) outline the opportunities and challenges for more traditional "High Touch" research (e.g. focus groups) and modern "High Tech" approaches (e.g. online communities).

Lavallee D, Wicks P, Cristancho A, Mullins D (2014) Stakeholder Engagement in Patient Centered Research: High Touch or High Tech? Expert Review of Pharmacoeconomics & Outcomes Research, 14(3):334-44

How Digital Technology and Patient Empowerment is Influencing the Future Direction of Clinical Trials

Primary community: General Collaborator: N/A

In this Future Medicine e-book chapter, Paul Wicks (PatientsLikeMe), Craig Lipset (Pfizer), and Tjeerd Van Staa (Clinical Practice Research Datalink) discuss the importance of trends in clinical trials; participant-led research using online communities, "virtual" clinical trials conducted remotely, and point-of-care trials carried out during routine clinical practice.

Wicks P, van Staa T, Lipset C (2014) How digital technology and patient empowerment is influencing the future direction of clinical trials. In: Chevret S & Resche-Rigon M (Eds.) Advances in Collating and Using Trial Data. Future Science. London.

Subjects No More: What Happens When Trial Participants Realize They Hold the Power?

Primary community: General Collaborator: N/A

In this editorial, the PatientsLikeMe research team explores how online tools have the potential to affect the blinding of randomized controlled clinical trials. As patients have found it easier to connect online, so too have they started organizing online; they've begun sharing their data, and even attempting to run their own analyses as to whether the trials they are enrolled in might yield benefits before the study has concluded. To address this, our team argues that a new social contract must be drawn up that respects the autonomy of patients as individuals while also maintaining scientific rigour, a challenge that must be faced before trials are irrevocably harmed.

Wicks P, Vaughan TE, Heywood J (2014) Subjects No More: What Happens When Trial Participants Realize They Hold the Power? British Medical Journal, 348:g368

Social Networking Sites and the Continuously Learning Health System

Primary community: General Collaborator: Institute of Medicine

There have been rapid increases in the use of online social networking sites for sharing health experiences like disease diagnosis, treatments, or methods for coping with illness. This discussion paper by the Institute of Medicine cites the results of our PatientsLikeMe survey that revealed 92% of users agreed with sharing their health data with researchers and as many as 78% would let drug companies see the same information. Around three quarters believed their health data could be used without their knowledge, or to deny them benefits or job opportunities, but they continued to share their data anyway.

Grajales F, Clifford D, Loupos P, Okun S, Quattrone S, Simon M, Wicks P, Henderson D (2014) Social Networking Sites and the Continuously Learning Health System: A Survey, Institute of Medicine Discussion Paper, National Academy of Sciences

Quality of Life in Organ Transplant Recipients Participating in an Online Transplant Community

Primary community: Organ Transplant Collaborator: Novartis

Online communities represent one mechanism to continue engaging organ transplant recipients in research after they have left the hospital. In this study, we explored how members of PatientsLikeMe's transplant community differ from the broader U.S population and the challenges they face to maximize their quality of life.

Wicks P, Sulham KA, Gnanasakthy A (2014) Quality of Life in Organ Transplant Recipients Participating in an Online Transplant Community, The Patient 7:73-84

Feasibility of a Web-Based Survey of Hallucinations and Assessment of Visual Function in Patients with Parkinson's Disease

Primary community: Parkinson's Disease Collaborator: Harvard Medical School

Assessing vision is an important task of care, but trained ophthalmologists are in short supply. Partnering with the Mass Eye and Ear Infirmary we sought to assess the feasibility of online vision testing using online methods to identify problems with visual contrast sensitivity and hallucinations, comparing people with Parkinson's to disease controls. Online vision testing is feasible and could be cost-effective for screening.

Jackson ML, Bex PJ, Ellison JM, Wicks P, Wallis J (2014) Feasibility of a Web-Based Survey of Hallucinations in Patients with Parkinson's Disease, Interactive Journal of Medical Research 3(1):e1

2013

The Virtuous Circle of the Quantified Self: A Human Computational Approach to Improved Health Outcomes

Primary community: General Collaborator: Max Little

The past 30 years have seen the introduction of a new form of distributed problem solving – patients helping one another using digital technologies. In this book chapter from the Handbook of Human Computation, TED Fellows Paul Wicks and Max Little recount the history of the e-patient movement (electronic, engaged, and empowered) and discuss the possibilities for crowd-sourcing medical data through devices and social networks .

Wicks P, Little M (2013) The Virtuous Circle of the Quantified Self: A Human Computational Approach to Improved Health Outcomes. In Michelucci, P. (ed.) Handbook of Human Computation

Virtual Visits for Parkinson's Disease

Primary community: Parkinson's disease Collaborator: Johns Hopkins

Parkinson's patients benefit immensely from seeing a movement disorder specialist. However, these doctors are few and far between, and Parkinson's symptoms make it difficult for patients to travel. Virtual visits that utilize webcams may help bridge the gap and in this study, 55 patients were offered this type of hour-long appointment. The high degree of satisfaction suggests these telemedicine consultations could effectively supplement real-world clinic visits.

Venkataraman V, Donohue SJ, Biglan KM, Wicks P, Dorsey ER (2013) Virtual visits for Parkinson's disease, Neurology Clinical Practice, e-pub online December 2013

Patient-Reported Outcome Measures in Safety Event Reporting: PROSPER Consortium Guidance

Primary community: General Collaborator: PROSPER Consortium

The PROSPER consortium comprises industry, regulatory authority, academic, private sector and patient representatives who are interested in the area of patient-reported outcomes of adverse events (PRO-AEs). While current safety reporting and risk assessment processes remain heavily dependent on healthcare professionals, these guidelines lay out a path to wider acceptance of patient reported safety reporting.

Banerjee AK, Okun S, Edwards RI, Wicks P, Smith MY, Mayall SJ, Flamion B, Cleeland C, Basch E (2013) Patient-Reported Outcome Measures in Safety Event Reporting: PROSPER Consortium Guidance, Drug Safety, 36:1129-1149

Making the Case for Continuous Learning from Routinely Collected Data

Primary community: General Collaborator: Institute of Medicine

The IOM believes in a "learning health system," but that system cannot rely solely on sporadic and expensive randomized clinical trials or academic studies. The data that is collected continuously as part of routine care, whether through electronic medical records or shared by patients themselves, must be harnessed to forge the new system.

Okun S, McGraw D, Stang P, Larson E, Goldmann D, Kupersmith J, Filart R, Robertson RM, Grossman C, Murray M (2013) Making the case for continuous learning from routinely collected data, Institute of Medicine Discussion Paper, National Academy of Sciences

Innovations in e-health

Primary community: General Collaborator: ISOQOL

Social networks form just one part of the new wave of innovations in E-health. In this editorial from a panel at the International Society of Quality of Life Researchers (ISOQOL), a person living with Parkinson's disease, a pediatric oncologist, a researcher, and a physiotherapist share their perspectives on the potential for these new technologies to improve patient outcomes.

Wicks P, Stamford J, Grootenhuis MA, Haverman L, Ahmed S (2013) Innovations in e-health, Quality of Life Research, e-pub ahead of print online July 14th 2013

Evaluation of an Online Platform for Multiple Sclerosis Research: Patient Description, Validation of Severity Scale, and Exploration of BMI Effects on Disease Progression

Primary community: Multiple sclerosis Collaborator: Brigham & Women's

PatientsLikeMe represents a new type of real-world evidence, and that requires constant comparison and validation against existing data sources. In partnership with the Partners Multiple Sclerosis Center at Brigham & Women's Hospital we found that members of PatientsLikeMe were slightly younger and more likely to be female, but that the differences were very small. We also validated the MSRS-R as a patient-reported outcome against a neurological examination and observational testing.

Bove R, Secor E, Healy BC, Musallam A, Vaughan T, Glanz BI, Weiner HL, Chitnis T, Wicks P, de Jager PL (2013) Evaluation of an online platform for multiple sclerosis research: Patient description, validation of severity scale, and exploration of BMI effects on disease progression, PLoS ONE 8(3): e59707

Blog: The Patient Engagement Pill – Lessons from Epilepsy

Primary community: Epilepsy Collaborator: UCSF School of Medicine

As part of a special issue on "patient engagement" funded by PCORI and the Robert Wood Johnson Foundation, PatientsLikeMe was invited to write a blog post for Health Affairs, often described as the "Bible" of health policy. In this piece we ask: If patient engagement was a pill, what would it look like? Who would make it? How would it be distributed? Patients themselves may be the secret ingredient.

Wicks P, & Hixson JD (2013) Blog: The Patient Engagement Pill – Lessons from Epilepsy, Health Affairs Blog, February 7th, 2013

Quantifying Short-Term Dynamics of Parkinson's Disease Use Self-Reported Symptom Data from an Internet Social Network

Primary community: Parkinson's disease Collaborator: MIT

Could frequent patient-reported data tell us more about a disease than clinical trial data? We collaborated with Oxford/MIT mathematician and TED Fellow Dr. Max Little to assess the shape and variability of Parkinson's disease on PatientsLikeMe compared to publicly available clinical trial data-set, DATATOP. Using the validated, self-reported UPDRS-III Sections 1 & 2, we found that even random fluctuations experienced by patients week-to-week may be as large as the "clinically meaningful" differences identified in trials.

Little MA, Wicks P, Vaughan TE, Pentland AS (2013), Quantifying short-term dynamics of Parkinson's disease use self-reported symptom data from an internet social network, Journal of Medical Internet Research, 15(1):e20

2012

Chapter: Web-based Resources

Primary community: ALS/MND Collaborator: ALS Research Group

Given our experience in helping patients with ALS to successfully harness the Internet to improve their care, we were commissioned by the ALS Research Group to write a chapter in the latest handbook for doctors treating these patients.

Wicks P & Heywood J (2012) Web-based resources. In: Bedlack RS & Mitsumoto H (Eds.) Amyotrophic Lateral Sclerosis: A Patient Care Guide for Clinicians

Chapter: The Evolving E-Patient

Primary community: General Collaborator: N/A

Two of our leading nurses, Sally Okun and Christine Caligtan, were invited to contribute to a core textbook on health informatics and provide their unique insights on the patient perspective.

Okun S, Caligtan C (2012) The Evolving E-Patient. In: Nelson R & Staggers N (Eds.) Health Informatics: An interprofessional approach

Patient Assessment of Physician Performance of Epilepsy Quality-of-Care Measures

Primary community: Epilepsy Collaborator: AAN

"Quality Measures" are guidelines proposed by specialist institutions such as the American Academy of Neurology (AAN) to the National Quality Forum (NQF) in diseases like epilepsy. In this study we partnered with the chair of the AAN's Epilepsy quality measures group to survey patients for their views of whether quality measures were being performed correctly. We found different rates of quality between physician specialties and made recommendations for future training of neurologists.

Wicks P & Fountain NB (2012) Patient assessment of physician performance of epilepsy quality-of-care measures, Neurology Clinical Practice, 2:335-345

The Multiple Sclerosis Rating Scale, Revised (MSRS-R): Development, Refinement, and Psychometric Validation Using an Online Community

Primary community: Multiple sclerosis Collaborator: N/A

PatientsLikeMe offers researchers novel ways of developing, validating, and refining patient reported outcome measures or PROs. In this paper, we report on our work to develop a new scale that helps patients with multiple sclerosis (MS) measure their disability over time. The concise, simple instrument was released under a Creative Commons license so it can be used or altered by anyone.

Wicks P, Vaughan TE, Massagli MP (2012) The Multiple Sclerosis Rating Scale, Revised (MSRS-R): Development, Refinement, and Psychometric Validation Using an Online Community, Health and Quality of Life Outcomes, 10(70)

Communicating with Patients on Healthcare Evidence

Primary community: General Collaborator: Institute of Medicine

The IOM states that "by the year 2020, 90 percent of clinical decisions will be supported by accurate, timely, and up-to-date clinical information, and will reflect the best available evidence." In this white paper, the IOM outlines data and best practices for communicating evidence to patients facing decisions.

Alston C, Paget L, Halvorson G, Novelli B, Guest J, McCabe P, Hoffman K, Koepke C, Simon M, Sutton S, Okun S, Wicks P, Undem T, Rohrbach V, Von Kohorn I (2012) Communicating with Patients on Healthcare Evidence, Institute of Medicine Discussion Paper, National Academy of Sciences

Perceived Benefits of Sharing Health Data Between People with Epilepsy on an Online Platform

Primary community: Epilepsy Collaborator: UCB

In this survey of our users, our epilepsy community (sponsored by UCB) demonstrated significant perceived benefits (improved seizure knowledge, medication adherence, reduced ER visits), but also underscored significant need; prior to joining the site, a third of epilepsy patients had never met another epilepsy patient.

Wicks P, Keininger DL, Massagli MP, de la Loge C, Brownstein C, Isojarvi J, Heywood J (2012) Perceived benefits of sharing health data between people with epilepsy on an online platform, Epilepsy and Behavior, 23:16-23

Online Assessment of ALS Functional Rating Scale Compares Well to In-Clinic Evaluation: A Prospective Trial

Primary community: ALS/MND Collaborator: Charité University Hospital

How does patient reported data compare to the clinician's view? In this collaboration with the Charité University Hospital in Berlin, we compared patients' self-reported ALS function scores that were collected over the Internet to the scores generated by the associated clinical teams; they correlated r=0.96.

Maier A, Holm T, Linke P, Münch C, Wicks P, Meyer T (2012) Online assessment of ALS functional rating scale compares well to in-clinic evaluation – a prospective trial, Amyotrophic Lateral Sclerosis, 13:210-216

Core Principles & Values of Effective Team-Based Health Care

Primary community: General Collaborator: Institute of Medicine

As we shift from acute infections and late-detected malignancies to chronic and long-term illnesses, the need for multi-disciplinary and team-based care becomes ever greater. In this discussion paper from the IOM, participants discussed the optimization of team-based care.

Mitchell P, Wynia M, Golden R, McNellis B, Okun S, Webb CE, Rohrbach V, Von Kohorn I (2012) Core principles & values of effective team-based health care, Institute of Medicine Discussion Paper, National Academy of Sciences

Reassessing Received Wisdom in ALS – Pain is Common When Studied Systematically

Primary community: ALS/MND Collaborator: N/A

After a population registry identified a high rate of pain in a representative sample of patients with ALS, R&D Director Paul Wicks was invited to write an editorial about how listening to patients can help researchers and clinicians overcome and update some of the widely held misconceptions about ALS (e.g., pain, cognitive dysfunction, or bedsores are uncommon).

Wicks P (2012) Editorial - Reassessing received wisdom in ALS – pain is common when studied systematically, European Journal of Neurology, 19(4):531:532

Information Wants to be Free, But When it Comes to Clinical Trials, Can We Afford to Let it Be?

Primary community: General Collaborator: N/A

An editorial by our R&D Director considers the impact of patient-centeredness and the availability of data as it relates to clinical trials. While patients sharing their data can accelerate research, we may also need to re-think how we "blind" patients in traditional randomized control trials.

Wicks P (2012) Editorial - "Information wants to be free" - But when it comes to clinical trials, can we afford to let it be? Clinical Investigation, 2(2):125-127

Mining Online Social Network Data for Biomedical Research: A Comparison of Clinicians' and Patients' Perceptions About Amyotrophic Lateral Sclerosis Treatments

Primary community: ALS/MND Collaborator: University of Utah

How do patients and doctors differ in their perceptions of systematic treatments in ALS? In collaboration with the University of Utah, we compared the passively entered symptom and treatment data on PatientsLikeMe to an earlier study from the published literature. We found that doctors and patients broadly agree but that patients suggested a number of new treatment options being used.

Nakamura C, Bromberg M, Bhargava S, Wicks P, Zeng QT (2012) Mining Online Social Network Data for Biomedical Research: A Comparison of Clinicians' and Patients' Perceptions about ALS Treatments. Journal of Medical Internet Research, 14(3):e90

2011

Accelerated Clinical Discovery using Self-Reported Patient Data Collected Online and a Patient-Matching Algorithm

Primary community: ALS/MND Collaborator: N/A

Following the publication of a small Italian study that provocatively suggested the drug lithium could slow ALS, hundreds of patients started taking the drug. Using an innovative data collection system and matching algorithm, we refuted this study with a sample ten times larger than the original trial.

Wicks P, Vaughan TE, Massagli MP, Heywood J (2011) Accelerated clinical discovery via open data platform and patient-matching algorithm, Nature Biotechnology, 29(5):411-414

Use of an Online Community to Develop Patient-Reported Outcome Instruments: The Multiple Sclerosis Treatment Adherence Questionnaire (MS-TAQ)

Primary community: Multiple sclerosis Collaborator: Novartis

Since the launch of our multiple sclerosis (MS) community in 2007, our users have been sharing their frustrations with using the current range of needle-based disease modifying treatments available to slow their progression. Needle-based treatments are burdensome and may have an impact on adherence; in this study, we used our online community to construct a novel rating scale of barriers to adherence that was a more accurate predictor of missed doses than clinical or demographic variables.

Wicks P, Massagli M, Kulkarni A, Dastani H (2011) Online Development of A Tool to Measure Barriers to Adherence: The Multiple Sclerosis Treatment Adherence Questionnaire (MS-TAQ), Journal of Medical Internet Research, 13(1):e12

Patient-Reported Outcomes as a Source of Evidence in Off-Label Prescribing: Analysis of Data from PatientsLikeMe

Primary community: General Collaborator: N/A

PatientsLikeMe members report taking treatments for a variety of indications, some of which have been approved by the FDA, others that haven't and are considered "off-label." In this study (winner of the Medicine 2.0 inaugural award), we analyzed the pattern of off-label usage for two drugs; amitriptyline and modafinil.

Frost J, Okun S, Vaughan T, Heywood J, Wicks P (2011) Patient-reported Outcomes as a Source of Evidence in Off-Label Prescribing: Analysis of Data From PatientsLikeMe, Journal of Medical Internet Research, 13(1):e6

Concordance Between Site of Onset and Limb Dominance in Amyotrophic Lateral Sclerosis

Primary community: ALS/MND Collaborator: Oxford University

In collaboration with Oxford University, we found a statistically significant association between site of arm-onset symptoms in ALS and handedness. This was not found in the leg-onset patient group, which lends evidence to the theory that ALS is related to lifetime exertion of affected limbs or neurological pathways.

Turner MR, Wicks P, Brownstein CA, Massagli MP, Toronjo M, Talbot K, Al-Chalabi A (2011) Concordance between site of onset and limb dominance in amyotrophic lateral sclerosis, Journal of Neurology, Neurosurgery, and Psychiatry, 82(8)853-4

Potential for Electronic Health Records and Online Social Networking to Redefine Medical Research

Primary community: General Collaborator: N/A

There is a broader movement of electronic health records and online tools for the purpose of information sharing and participation in research. This paper by PatientsLikeMe geneticist Dr. Catherine Brownstein and colleagues maps out opportunities like pharmacovigilance, comparative effectiveness, research, and what some of the potential challenges will be for electronic and observational studies.

Pearson JF, Brownstein CA, Brownstein JS. (2011) Potential for electronic health records and online social networking to redefine medical research. Clinical Chemistry, 57(2):196-204.

2010

Sharing Health Data for Better Outcomes on PatientsLikeMe

Primary community: General Collaborator: N/A

After collecting anecdotal evidence that the site was having a positive effect on our members over time, the PatientsLikeMe "user survey" found that patient members reported a number of perceived benefits, including greater health literacy, improved quality of life, and greater social support as a result of using the site.

Wicks P, Massagli M, Frost J, Brownstein C, Okun S, Vaughan T, Bradley R, Heywood J (2010) Sharing Health Data for Better Outcomes on PatientsLikeMe, Journal of Medical Internet Research, 12(2):e19

Modifiable Barriers to Enrollment in American ALS Research Studies

Primary community: ALS/MND Collaborator: ALS Research Group / NEALS

As part of an effort to enroll more ALS patients in a study carried out in collaboration with MGH and the Northeast ALS Consortium, we attempted to understand why some patients chose not to participate. We found that ALS patients frequently misunderstood the research process (e.g., believing that a blood sample given for a routine lab test would automatically be reused for genetic discovery).

Bedlack RS, Wicks P, Heywood J, Karsarskis E (2010) Modifiable Barriers to Enrollment in American ALS Research Studies, Amyotrophic Lateral Sclerosis, Dec;11(6):502-7

The Potential Research Impact of Patient Reported Outcomes on Osteogenesis Imperfecta
Primary community: Osteogenesis imperfect Collaborator: N/A

We have been invited on several occasions to design what our "vertical communities" might look like in different applications. This paper describes what a community for patients with osteogenesis imperfecta might look like.

Brownstein CA, Wicks P (2010) The Potential Research Impact of Patient Reported Outcomes on Osteogenesis Imperfecta, Clinical Orthopedics and Related Research, 468(10):2581-2585

The PatientsLikeMe Multiple Sclerosis Community: Using Online Marketing to Shift the Health Data Privacy Paradigm
Primary community: Multiple sclerosis Collaborator: N/A

Designing a clinically relevant and scientifically valid community is important, but if we can't get any patients to visit it then it can't do much good! In this paper, Chief Marketing Officer David Williams explains how we executed the marketing launch of our MS community through segmentation, PR, and targeted recruitment.

Williams III, D (2010) The PatientsLikeMe® Multiple Sclerosis Community: Using online marketing to shift the health data privacy paradigm, Journal of Communication in Healthcare, 3(1):48-61

2009

Measuring Function in Advanced ALS: Validation of ALSFRS-EX Extension Items
Primary community: ALS/MND Collaborator: ALS patient member

One of our patients, Cathy Wolf, has had ALS for more than 10 years and has been a psychologist engaged in research for 30+ years. She expressed dissatisfaction in our forum that the ALSFRS-R, the "gold standard" measure of ALS function, was insensitive at lower levels. Patients like her, or Stephen Hawking, could be rated a zero in terms of function, despite the fact they could still work, use the computer, and manage their affairs. With her help as a co-investigator, we developed an extension to the ALSFRS-R that is in use today in clinical research.

Wicks P, Massagli M, Wolf C, Heywood J (2009) Measuring function in advanced ALS: Validation of the ALSFRS-R extension items, European Journal of Neurology, 16(3):353-359

[The Power of Social Networking in Medicine]
Primary community: General Collaborator: N/A

Following an article about PatientsLikeMe in *Nature Biotechnology*, we wrote this piece describing updates to our system and our work on the lithium experiment in ALS.

Brownstein C, Brownstein J, Williams D, Wicks P, Heywood J (2009) The power of social networking in medicine, Nature Biotechnology, 27(10):888-890

[Pathological Gambling Amongst Parkinson's Disease and ALS Patients in an Online Community (PatientsLikeMe.com)]
Primary community: ALS/MND and Parkinson's Collaborator: Southern General Hospital

After hearing complaints about compulsive gambling in our Parkinson's disease (PD) community resulting from medication side effects, we decided to compare our PD population to the literature. More of our members experienced compulsive gambling (13%) than had been reported in prior literature (~7%). We also used ALS as a control group so that we could compare two neurological populations, a rarity in clinical research.

Wicks P, Macphee GJ. (2009) Pathological gambling amongst Parkinson's disease and ALS patients in an online community (PatientsLikeMe.com), Movement Disorders, 24(7): 1085-1088

[PatientsLikeMe the Case For a Data-Centered Patient Community and How ALS Patients Use the Community to Inform Treatment Decisions and Manage Pulmonary Health]
Primary community: ALS/MND Collaborator: N/A

We were asked to consider what a community for patients with chronic obstructive pulmonary disease (COPD) might look like.

Frost J, Massagli M (2009) PatientsLikeMe the case for a data-centered patient community and how ALS patients use the community to inform treatment decisions and manage pulmonary health, Chronic Respiratory Disease, 6(4) 225–229

[Sharing Information with PatientsLikeMe]
Primary community: General Collaborator: N/A

As our patient communities expanded from ALS to other neurological conditions such as MS, Parkinson's disease, and the Parkinson's Plus syndromes, we were invited to share our experiences with the field journal for neuroscience nursing.

Wicks P (2009) Editorial - Sharing Information with PatientsLikeMe, British Journal of Neuroscience Nursing, 5(3):132-133

2008

How the Social Web Supports Patient Experimentation with a New Therapy: The Demand for Patient-Controlled and Patient-Centered Informatics

Primary community: ALS/MND Collaborator: N/A

In a paper presented at the American Medical Informatics Association (AMIA) annual meeting, we analyzed the uptake in forum conversations about the controversial drug lithium carbonate and its potential for use in the ALS population, including description of our lithium tool.

Frost J, Massagli MP, Wicks P, Heywood J (2008) How the Social Web Supports Patient Experimentation with a New Therapy: The demand for patient-controlled and patient-centered informatics, AMIA Annual Symposium Proceedings, 6:217-21.

PatientsLikeMe: Consumer Health Vocabulary as a Folksonomy

Primary community: General Collaborator: University of Wisconsin

In a second AMIA paper, we discussed the use of PatientsLikeMe as a platform to gather the patients' voice in describing symptoms and conditions. The goal was to compare patient descriptions with existing terminologies such as SNOMED, and potentially integrate them into these widely used databases.

Smith CA, Wicks P (2008) PatientsLikeMe: Consumer Health Vocabulary as a Folksonomy, AMIA Annual Symposium Proceedings, 6:682-6

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

Primary community: ALS/MND Collaborator: N/A

We analyzed interactions between members of our site and found that patients sharing their health data are willing to frequently engage in medically-focused conversations about their health and decision-making.

Frost JH, Massagli M (2008) Social Uses of Personal Health Information Within PatientsLikeMe, an Online Patient Community: What Can Happen When Patients Have Access to One Another's Data, Journal of Medical Internet Research, 10(3):e15

ALS Patients Request More Information About Cognitive Symptoms

Primary community: ALS/MND Collaborator: N/A

We asked the PatientsLikeMe ALS community to answer novel questions that would not normally attract the research funding or study numbers required to produce compelling answers. This was our first fully-fledged research study published in a peer-review journal, and it answered an important question that had previously driven physicians not to inform their patients about the possibility of cognitive symptoms of their disease. This study confirmed that bias and found conclusively that two-thirds of patients wanted to be told.

Wicks P, Frost J (2008) ALS patients request more information about cognitive symptoms, European Journal of Neurology, 15(5):497-500

2007

Excessive Yawning is Common in the Bulbar-Onset Form of ALS

Primary community: ALS/MND Collaborator: N/A

A case report published in *Acta Psychiatrica Scandinavica* prompted us to perform our own investigation of excessive yawning in our ALS population. We were able to go from idea conception to publication in less than 12 weeks.

Wicks P, (2007) Excessive yawning is common in the bulbar-onset form of ALS, Acta Psychiatrica Scandinavica, 116 (1):76