2018 ACR and 2019 PANLAR Abstracts

Arthritis patients with severe pain perceive greater challenges in coping with the emotional impact of living with a chronic disease

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Using a Mobile App to Facilitate Patient-Doctor Discussions to Make Informed Decisions Regarding "Painsomnia"

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"Doctor, a Storm Is Coming and My Joints Hurt": Evaluating Associations between Weather Changes and Arthritis Symptoms

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Enhancing Patient Ability to Process and Use Information about Medication Risks and Benefits

Genevieve Hickey[1], Caprice Hunt[1], Molly Keebler[2], Delesha M. Carpenter[3], Elizabeth (Blair) Solow[4], Valerie Reyna[5], W. Benjamin Nowell[6], Cynthia Edmonds[1], Kimberlee O'Neill[1] and Susan J. Blalock[1], [1]Eshelman School of Pharmacy, University of North Carolina at Chapel Hill, Chapel Hill, NC, [2]Center for BrainHealth, University of Texas Dallas, Dallas, TX, [3]Eshelman School of Pharmacy, University of North Carolina at Chapel Hill, Asheville, NC, [4]UT Southwestern Rheumatology, Dallas, TX, [5]Cornell University, Ithica, NY, [6]Global Healthy Living Foundation, Upper Nyack, NY

Health-Related Quality of Life in Patients with Ankylosing Spondylitis in the United States

W. Benjamin Nowell[1], Regan Reynolds[1], Kelly Gavigan[1], Shilpa Venkatachalam[1], Marie de la Cruz[2], Emuella Flood[2], Ethan Schwartz[2], Beverly Romero[2], Yujin Park[3] and Alexis Ogdie[4], [1]Global Healthy Living Foundation, Upper Nyack, NY, [2]ICON, Gaithersburg, MD, [3]Novartis Pharmaceuticals Corporation, East Hanover, NJ, [4]Perelman School of Medicine, University of Pennsylvania, Philadelphia, PA

Privacy-Preserving Linkage between the ArthritisPower Registry and Commercial Payer Claims Data to Support Comparative Effectiveness and Outcomes Research Registry

W. Benjamin Nowell[1], Jeffrey R. Curtis[2], Lang Chen[2], Biruk Eshete[3], Abiy Agiro[3], Xiaoxue Chen[3], Jennifer Ostertag-Stretch[3], Toan Ong[4], Kelly Clayton[1], Kelly Gavigan[1] and Kevin Haynes[3], [1]Global Healthy Living Foundation, Upper Nyack, NY, [2]University of Alabama at Birmingham, Birmingham, AL, [3]HealthCore, Wilmington, DE, [4]University of Colorado, Denver, CO

Examining Workplace Support in the Context of RA Disease Activity

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Understanding Patients' Perceptions of Gout

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Development of a Rheumatoid Arthritis Global Outcome Measure to Enable Comparisons of Patient Experiences across Treatment Arms in Randomized Clinical Trials

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Arthritis patients with severe pain perceive greater challenges in coping with the emotional impact of living with a chronic disease

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Objectives:

For people living with rheumatic and musculoskeletal disease (RMD), maintaining a healthy weight through proper diet and exercise is an important goal. For providers managing patients (pts) with RMD, it is important to understand what pts' motivations and challenges are in accomplishing this goal. Pain is the most important symptom for most arthritis patients and its severity may affect their participation in health behavior change programs. This study aimed to examine motivations of US adults with inflammatory arthritis and osteoarthritis to engage in a peer-support diet and exercise intervention, and explore differences in motivation based on pain severity.

Methods:

A 37-item cross-sectional survey was developed in partnership with RMD pt partners and administered online and via a mobile app in the ArthritisPower research registry. Pts were eligible if they were ≥ 19 years of age, resided in the US, and reported a physician diagnosis of inflammatory arthritis or osteoarthritis. Pts reported on their use of technology and social media, experience with exercise and weight loss programs, and interest in a social media weight loss intervention. We descriptively reported differences between respondents with and without severe pain (SP) as measured by the NIH PROMIS-CAT for Pain Interference (SP: t-score ≥ 70).

Results:

418 pts participated, with mean age 56 (10.5), 89.5% white, 89.5% female, mean BMI 32.6 (8.9). More SP than non-SP pts were obese (BMI > 30; 66% vs. 54%, p=0.08). On a 0-10 scale (10=very much), pts were asked to rate how much arthritis impeded their ability to lose weight; pts with SP had higher mean interference (7.3 [2.5]) than non-SP pts (5.6 [2.8], p<0.001). Pts with SP indicated that arthritis impeded their ability to exercise to a greater extent than non-SP pts (8.6 [1.9] vs. 6.8 [2.8], p<0.001). More SP than non-SP pts reported coping with the emotional impact of their disease as a challenge to arthritis management (76.3% vs. 50.7%, p<0.001) and more SP than non-SP pts identified depression (67.8% vs. 33.2%, p<0.001) and anxiety or stress (49.2% vs. 32.6%, p=0.01) as challenges to losing weight.

Conclusions:

Pts with SP from arthritis face unique challenges in managing arthritis and achieving a healthy weight. To meet the needs of these patients, arthritis self-management and weight loss programs may need to emphasize coping strategies.

Using a Mobile App to Facilitate Patient-Doctor Discussions to Make Informed Decisions Regarding "Painsomnia"

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Background/Diagnosis:

As a patient with AS, Dawn founded #SpoonieChat to provide a space on twitter for people living with chronic diseases to support each other. One common theme in #SpoonieChat is the relationship between pain and sleep. 'Painsomnia' is a patient-generated term that addresses this cycle of pain and insomnia.

A follower of #SpoonieChat who experiences painsomnia is Shelley. Shelley was diagnosed with RA in 2012, following symptoms of symmetrical joint pain in hands and toes; fatigue, and malaise. After treatments including methotrexate, Plaquenil, and 5+ biologics, Shelley has made significant lifestyle changes and is currently on Rituximab. In addition to monthly bloodwork and physician exams, changes in Shelley's treatment are based on her own data gathered by weekly symptom tracking.

To understand patients' adaptations to manage painsomnia we used collective knowledge generated from #SpoonieChat with Shelley's unique experiences as an individual patient recorded through patient reported outcomes measures via ArthritisPower.

Treatment:

ArthritisPower is a patient-led, patient-generated, app-based research registry for arthritis, bone and inflammatory skin conditions and is free to use for patients like Shelley to track symptoms, to record subtle changes, to see how they are doing over a period of time whether on a new medication and/or in connection to sleep, physical function and other measures.

 By tracking pain interference, Shelley has found pain to be interrelated with levels of fatigue, sleep quality, and cognitive issues, thereby negatively impacting her quality of life. Figure 1 shows Shelley's pain interference scores over a six-month period. Shelley identifies the causes of fluctuations by also tracking dates of flares, steroid usage, periods of illness, and restful vacations.

Maintenance:

Through this approach, Shelley worked with her rheumatologist to lessen the symptoms and progression of RA. Shelley continues to track these elements through ArthritisPower to look for patterns influenced by medication and maintenance strategies including diet, exercise, decreasing stress, and increasing sleep. This provides the doctor with information beyond blood work, lab tests and swollen joint counts to work with Shelley in managing her condition and treating the things that matter to her to help her live a better quality of life.

Quality of Life:

Doctor and patient conversations can be more meaningful when patient experienced data is systematically collected and discussed. Data gathered through ArthritisPower gives patients like Shelley, an organized way to talk with their doctor on each of the indicators of pain and sleep which affect cognitive function, physical function, depression.

"Doctor, a Storm Is Coming and My Joints Hurt": Evaluating Associations between Weather Changes and Arthritis Symptoms

Jeffrey R. Curtis[1], Shuo Yang[1], Cassie Clinton[1], Lang Chen[1], W. Benjamin Nowell[2], Huifeng Yun[1] and David Curtis[3], [1]University of Alabama at Birmingham, Birmingham, AL, [2]Global Healthy Living Foundation, Upper Nyack, NY, [3]Global Healthy Living Foundation, New York, NY

Background/Purpose:

Arthritis symptoms reported by patients have been anecdotally associated with weather changes, but large-scale, systemic evaluations are few in number. A variety of parameters associated with weather that might underlie arthritis-related pain and related symptoms have been inconsistently reported.

Methods:

Patients participating in the ArthritisPower registry and contributing data via a Smartphone or computer App from the continental U.S. were eligible for analysis. Geolocation (latitude/longitude) was extracted from the Smartphone's physical location or computer IP address. Various weather parameters (e.g. temperature, humidity, wind speed/direction, barometric pressure) were obtained from the nearest National Oceanic and Atmospheric Administration (NOAA) weather station based on patient's geolocation. Various restrictions in the maximal allowable distance to the nearest weather station (e.g. <25 miles) were evaluated. Patient disease activity by the RAPID3, and patient reported outcomes (PROs) including pain interference, fatigue and physical function measured by the NIH PROMIS instruments (using computer adaptive testing) were obtained from the registry, and associated with NOAA weather data at that same time (to the nearest hour) and location, and at the same location 24 hours before and after each patient observation. Cross-sectional correlation between various weather parameters and PROs were quantified as r values using Pearson correlation coefficients. A "cold front" definition was proposed based on the confluence of longitudinal change over 3 days in relative humidity, wind direction, barometric pressure, and dew point.

Results:

At the time of this analysis, 1334 unique patients contributed 2425 PRO observations with linkable NOAA weather data. Mean(SD) age was 53.9(10.3) years, 91% women, 90% white. In terms of various arthritis conditions represented in ArthritisPower, 45% had rheumatoid arthritis, 10% psoriatic arthritis, 9% ankylosing spondylitis, and 62% osteoarthritis (with or without a concomitant inflammatory arthritis). Many of the correlations between various weather parameters and PROs were statistically significant ($p < 0.001$) albeit numerically weak (all r values < 0.2). For patients contributing any PRO data at the time of an evolving cold front using the proposed definition, patient symptoms were not different as measured by various PROs (Table).

Conclusion:

Weather is quantitatively related to patient's arthritis symptoms. Additional work is ongoing to refine specific weather parameters and their associations with PROs in order to provide potentially actionable information to patients and their healthcare providers.

Enhancing Patient Ability to Process and Use Information about Medication Risks and Benefits

Genevieve Hickey[1], Caprice Hunt[1], Molly Keebler[2], Delesha M. Carpenter[3], Elizabeth (Blair) Solow[4], Valerie Reyna[5], W. Benjamin Nowell[6], Cynthia Edmonds[1], Kimberlee O'Neill[1] and Susan J. Blalock[1], [1]Eshelman School of Pharmacy, University of North Carolina at Chapel Hill, Chapel Hill, NC, [2]Center for BrainHealth, University of Texas Dallas, Dallas, TX, [3]Eshelman School of Pharmacy, University of North Carolina at Chapel Hill, Asheville, NC, [4]UT Southwestern Rheumatology, Dallas, TX, [5]Cornell University, Ithica, NY, [6]Global Healthy Living Foundation, Upper Nyack, NY

Background/Purpose:
Guidelines for the treatment of rheumatoid arthritis (RA) underscore the importance of an early and targeted approach to control inflammation. However, patients are often reluctant to agree to aggressive therapy when they believe their symptoms are tolerable, despite high disease activity scores. This study is based on the premise that educating patients about treatment risks and benefits requires a two-pronged approach: (1) Simplifying written materials to reduce user burden and (2) Teaching patients the skills needed to process complex information. DrugFactsBoxes® are designed to address the former; Gist Reasoning (GIST) Training is designed to address the latter.

Methods:
The study is a randomized controlled trial in which participants with doctor-diagnosed RA are randomized to one of four groups: (1) Medication Guide without GIST Training, (2) Medication Guide with GIST Training, (3) DrugFactsBox® without GIST Training, and (4) DrugFactsBox® with GIST Training. Data are collected at baseline (prior to intervention implementation) and at 6 weeks, 3 months, and 6 month follow-up. The primary outcome is informed decision making regarding the use of disease-modifying anti-rheumatic drugs (DMARDs). Patients using a DMARD are classified as having made an informed decision if they have adequate knowledge (≥85 on a 100 point scale) and values that favor aggressive treatment of RA. Patients not using a DMARD are classified as having made an informed decision if they have adequate knowledge and have values that do not favor aggressive treatment. Knowledge is a secondary outcome variable. Data were analyzed using logistic and linear regression.

Results:
Data collection is ongoing. To date, 297 participants have completed baseline data collection and 135 have completed the 6-month follow-up. Controlling for baseline knowledge, participants assigned to GIST Training exhibited greater knowledge at the 6-month follow-up, compared to those not assigned to training (Means: 86.1 vs 83.4, p =.06). In a logistic regression predicting informed decision making at the 6-month follow-up, there was a significant interaction between (1) whether the participant met the criteria for informed decision making at baseline and (2) assignment to GIST Training (p=.003). Among those classified as not meeting the criteria for informed decision making at baseline, 56.7% (n=17) of those assigned to GIST Training met the criteria at the 6-month follow-up, compared to 25% (n=11) of those not assigned to training (p=.007). However, among those classified as meeting the criteria at baseline, 35.0% (n=7) of those assigned to GIST Training did not meet the criteria at the 6-month follow-up, compared to 14.7% (n=5) of those not assigned to training (p=.09). No differences were observed between those randomized to Medication Guides versus DrugFactsBox®.

Conclusion:
These findings provide preliminary support for the effectiveness of GIST Training in helping patients develop the skills needed to process complex information about medication risks/benefits. RA Treatment benefits appear to be limited to those who do not meet the criteria for informed decision making prior to the initiation of training.

Health-Related Quality of Life in Patients with Ankylosing Spondylitis in the United States

W. Benjamin Nowell[1], Regan Reynolds[1], Kelly Gavigan[1], Shilpa Venkatachalam[1], Marie de la Cruz[2], Emuella Flood[2], Ethan Schwartz[2], Beverly Romero[2], Yujin Park[3] and Alexis Ogdie[4], [1]Global Healthy Living Foundation, Upper Nyack, NY, [2]ICON, Gaithersburg, MD, [3]Novartis Pharmaceuticals Corporation, East Hanover, NJ, [4]Perelman School of Medicine, University of Pennsylvania, Philadelphia, PA

Background/Purpose:

Ankylosing spondylitis (AS) is a chronic, systemic, inflammatory disease that affects primarily the sacroiliac joints and spine and can cause irreversible damage. Measuring disease activity and quality of life of AS patients can be complex due to the slow progression and invisible nature of the disease. The objective of this web-based survey was to describe the impact of AS on health-related quality of life (HRQoL) from the US patient perspective.

Methods:

US adults aged ≥ 18 years with a self-reported diagnosis of AS were recruited through CreakyJoints (www.CreakyJoints.org), an online patient support community comprising patients with arthritis and arthritis-related diseases and their caregivers, as well as through outreach on social media. Respondents completed a web-based survey that was designed to collect information on sociodemographic characteristics, clinical symptoms, disease burden, and the impact of AS on work productivity and relationships.**Survey questions were developed following analysis of qualitative interviews of patients with AS and clinical experts, as well as a targeted literature review.** Survey results were compared between men and women using 2-sample t tests for continuous variables and chi squared tests for categorical variables.

Results:

Among 235 respondents, 174 (74.0%) were women, and the mean (SD) age was 49.8 (10.7) years. The mean (SD) and median (IQR) time since AS diagnosis was 8.5 (9.3) and 5.0 (2-12) years. Depression (62.1%), anxiety (54.5%), and fibromyalgia (35.7%) were the most commonly reported comorbidities among respondents. Women had significantly higher mean RAPID3 scores and lower PROMIS10 Global Physical and Mental Health T-Scores than men (**Table**). Approximately 90% of respondents reported either complete or partial unemployment due to AS. Most respondents (71.8%) had difficulty sitting or standing for long hours; other common issues related to work included missed work (47.0%), difficulty doing physical tasks (41.9%), and loss of productivity (41.0%) (**Table**). Although the impact of AS on work was not significantly different between men and women, the percentage of women with negative impact of AS on work was numerically higher in most categories. The most common impacts of AS on relationships were difficulty spending time with friends (62.6%), lack of understanding from friends and family about AS (54.0%), and difficulty spending time with family (46.8%) (**Table**).

Conclusion:

Whereas the study findings demonstrate a considerable impact of AS on patients' HRQoL including work productivity and relationships, these topics are often not discussed with their treating physicians, friends, and families. Encouraging patients to share their disease burden with their physicians and caregivers may help to optimize medical care and outcomes in patients with AS.

Privacy-Preserving Linkage between the ArthritisPower Registry and Commercial Payer Claims Data to Support Comparative Effectiveness and Outcomes Research Registry

W. Benjamin Nowell[1], Jeffrey R. Curtis[2], Lang Chen[2], Biruk Eshete[3], Abiy Agiro[3], Xiaoxue Chen[3], Jennifer Ostertag-Stretch[3], Toan Ong[4], Kelly Clayton[1], Kelly Gavigan[1] and Kevin Haynes[3], [1]Global Healthy Living Foundation, Upper Nyack, NY, [2]University of Alabama at Birmingham, Birmingham, AL, [3]HealthCore, Wilmington, DE, [4]University of Colorado, Denver, CO

Background/Purpose:
Integration of registry information with administrative claims data may be used to conduct patient-centered outcomes research (PCOR), including comparative effectiveness and safety studies, and to improve the quality of clinical care. While a variety of methods exist to link data, the unique requirements for linking data provided by patients in a research registry to claims data held by health plans and payers may present unique obstacles. These challenges are even greater if 1) no patient identifiers can be directly shared, and 2) no unique identifiers (e.g. social security number) are acceptable for use given privacy concerns. We evaluated results of a method to link data from a patient registry to the clinical outcomes research subsidiary of a large commercial payer under these two constraints.

Methods:
A novel, preliminarily validated encryption algorithm using a secure HIPAA-compliant cryptographic one-way hash function was developed to convert a vector of non-unique patient identifiers (first name, last name, sex, date of birth) into unique hashed identifiers. Both the ArthritisPower registry and HealthCore, Anthem Inc.'s research subsidiary, utilized the hashing algorithm and exchanged only these identifiers; exact match on the hashed identifiers was required. The diagnoses self-reported by patients in the ArthritisPower registry were compared with ICD9/10-based diagnoses in the claims data for the same conditions, and similar autoimmune conditions, varying the amount of health plan coverage available (any, or >5 years), using both a sensitive (>=1 outpatient diagnosis) and a more specific (>=2 diagnoses from relevant specialist) claims-based definition, and considering whether the condition matched exactly vs. matched a broader set of inflammatory arthritis diagnosis codes (e.g. RA, PsA, ankylosing spondylitis).

Results:
Of 11,343 ArthritisPower registry participants enrolled at time of data integration with any health condition, 19.1% (n=2166) were linked to Anthem claims data with no minimum coverage duration requirement; 1600 were commercially insured. Of these, mean (SD) age was 49 (10.7), 93% women, and they resided in the Northeast (12%), Midwest (29%), South (37%) and West (22%). Among patients with more than 5 years of coverage and who met the ICD9/10 definition for the computable phenotypes of RA, PsA or psoriasis, confirmation rates varied modestly according to the various parameters permuted (Table).

Conclusion:
Information from a patient-led arthritis research registry where in-person visits are not required can be linked to data from a research subsidiary of a large commercial payer using a hashing algorithm that does not require unique identifiers nor sharing of individual patient information. Ongoing work is underway to maximize the accuracy of linkage and confirmation rates using various approaches.

Examining Workplace Support in the Context of RA Disease Activity

W. Benjamin Nowell[1], Kelly Gavigan[1], Guillermo Ernest Gonzales[2], Shilpa Venkatachalam[1], Jeffrey R. Curtis[3], Sheiva Ghazanfari[4], Danielle Cavazzini[4] and Leticia Ferri[4], [1]Global Healthy Living Foundation, Upper Nyack, NY, [2]Silver School of Social Work, New York University, New York, NY, [3]University of Alabama at Birmingham, Birmingham, AL, [4]Bristol-Myers Squibb, Princeton, NJ

Background/Purpose:
RA can diminish patients' (pts) work productivity and increase the risk of long-term disability, economic insecurity and worsening health, but limited research informs these issues. The objective was to identify associations between RA and treatment status on pts' productivity and workplace support, using real-world data from the ArthritisPower registry.

Methods:
US-resident adult pts with physician-diagnosed RA and a history of or current DMARD use were surveyed from the ArthritisPower registry via smartphone or web app. Pt-reported outcomes included Patient-Reported Outcomes Measurement Information System (PROMIS) pain interference, fatigue, sleep disturbance, physical function, social participation and Routine Assessment of Pt Index Data 3 (RAPID3) score. The Work Productivity and Activity Impairment (WPAI) questionnaire was used to rate how RA affected pt work productivity for past 3 months (scale: 0 [no effect] to 10 [completely prevented from working]).

Results:
Of 296 pts, 88% were currently treated with DMARDs (non-biologic and biologic) and 74% had high disease activity (HDA) assessed by RAPID3 (>12). HDA was associated with lower education, lower employment and lower full-time employment, with a higher proportion of pts with HDA reporting being disabled ($p < 0.05$ for each). Average self-reported days missed from work due to problems associated with RA in the past 3 months differed between pts with and without HDA (6.1 vs 3.8 days, respectively; $p < 0.05$). Pts without HDA missed more work days for medical appointments than pts with HDA (2.6 vs 1.2 days, respectively). Pts with HDA missed more days due to side effects from RA treatment than pts without HDA (mean: 0.5 vs 0.1 days, respectively). RA affected work productivity to a greater extent in pts with HDA than without (WPAI scores 5.3 and 3.3, respectively; $p < 0.05$). Unemployed pts had more physically demanding tasks (e.g. heavy load lifting) in their most recent paid position than currently employed pts (Table 1). Pts who were employed had access to greater workplace flexibility (e.g. changes in start and finish times, working from home) than unemployed pts.

Conclusion:
Despite treatment with DMARDs, the majority of HDA pts with RA were more likely to be unemployed or disabled. Physically demanding tasks and less flexible work arrangements were associated with a higher unemployment rate. Attaining lower disease activity and facilitating workplace flexibility (i.e. assign fewer physical tasks, permit flexible hours) may help pts with RA remain employed. Work flexibility policies have been proposed or passed federally in 33 states, yet there is a need for greater visibility, compliance and accessibility to these options for pts with RA. Indirect costs of RA in the workplace should be considered when determining the total cost of RA care.

Understanding Patients' Perceptions of Gout

Kelly Gavigan[1], Kayla Jordan[2], Alexa Meara[3] and **W. Benjamin Nowell**[1], [1]Global Healthy Living Foundation, Upper Nyack, NY, [2]University of Texas at Austin, Austin, TX, [3]Internal Medicine/Rheumatology, The Ohio State University Wexner Medical Center, Columbus, OH

Background/Purpose:

Past research has shown that patients' (pts') knowledge of their disease influences health-related behavior. The objective of this study is to explore gout pts' knowledge of the disease, treatment options and chronic management, as well as identify their sources of health information. With only half of gout pts adherent to gout medications, our goal is to guide the development of gout support tools by identifying gaps in pt knowledge.

Methods:

We developed an online survey to gather information about pts' knowledge, beliefs and perceptions of gout. Pt members of the ArthritisPower registry or CreakyJoints community were asked to participate if they had a self-reported diagnosis of gout. Pts completed six (Pain Interference, Fatigue, Sleep Disturbance, Physical Function, RAPID3, Gout Flare) pt-reported outcome measures. Pearson's Chi-squared test was used to assess significance. Open-ended questions were analyzed with LIWC2015, an automated text analysis program.

Results:

To date, 103 participants completed the survey; 55% were female, 53% had an annual income >=$50,000, 84% white and average age of 56 years (range 32 – 80). 85% believe uric acid causes gout, however, only 50% believe uric acid-controlling medication is the best way to manage the disease. Additionally, 81% believe gout is best managed by diet change. Pts currently experiencing a gout flare were more likely to believe gout is best managed with NSAIDs than those not experiencing a flare (37% vs 16%; p=0.02) (Table). The qualitative results showed that non-flaring pts tended to use risk-oriented language while flaring pts used reward-oriented language (Figure). Pts receive information about gout from online health education sites and their PCP at similar rates (60% and 53%, respectively). Non-flaring pts preferred to get information online more than flaring pts (63% vs. 44%; p=0.06). Men were more likely to seek information from their rheumatologist than women (28% vs 13%; p=0.05).

Conclusion:

The survey shows variation in beliefs about gout and in words used to describe gout by gender, age and gout flare status. Food and lifestyle misconceptions remain a large component of pts' conversations surrounding gout. The majority of pts currently believe gout can be managed through diet rather than prescribed medications, suggesting insufficient pt knowledge about gout. While many pts prefer to access information online, there is still an underutilization of rheumatologists. Developing decisional support tools available at health care offices may help increase knowledge about gout and improve gout health care outcomes.

Development of a Rheumatoid Arthritis Global Outcome Measure to Enable Comparisons of Patient Experiences across Treatment Arms in Randomized Clinical Trials

Liana Fraenkel[1], W. Benjamin Nowell[2], Carole Wiedmeyer[2], Zhenglin Wei[3], Kaleb Michaud[4], Tuhina Neogi[5], Christine Ramsey[1] and David Broniatowski[3], [1]Yale University School of Medicine, New Haven, CT, [2]Global Healthy Living Foundation, Upper Nyack, NY, [3]George Washington University, Washington, DC, [4]Rheumatology, University of Nebraska Medical Center, Omaha, NE, [5]Clinical Epidemiology Research and Training Unit, Boston University School of Medicine, Boston, MA

Background/Purpose:
Randomized controlled trials currently report benefits and adverse events (AEs) separately, and therefore do not permit comparisons of patients' overall experiences on one treatment versus another. The purpose of this study is to develop a Global Patient-Reported Outcome Measure (G-PROM) to quantify and compare the distribution of patients' overall experiences on medications.

Methods:
We invited rheumatoid arthritis (RA) patients who were part of an online community to complete a survey, based on Trajectory Mapping (TM) to generate a hierarchy of AEs. The TM survey establishes a hierarchy by enabling patients to indicate whether an AE is worse, better, or no better or worse than a referent AE. TM allows the construction of "equivalence classes" i.e., groups of AEs judged by patients as having a comparable impact on quality of life. We subsequently conducted a second survey in which participants (who did not participate in the initial TM survey) were asked to indicate their preference for pairs of outcomes, where each outcome include both a specified level of benefit [little or no improvement (ACR20 or less), some improvement (between ACR20 and 50), and major improvement (ACR50 and greater)] and an AE (see Figure 1).

Results:
195 participants completed the initial TM survey. The mean age was 53.5 (11.6), 89% were female, and 56% were college graduates. The initial TM survey generated 11 hierarchies of AEs. The final hierarchy (9 levels of AEs ranging from no AEs to serious AEs resulting in irreversible harm) was chosen based on goodness of fit parameters (see Figure 2). 426 participants with similar demographic characteristics completed the second survey. Ratings revealed that when paired with benefits, AEs clustered into 3 main groups: no, mild or manageable AEs (Levels 1-4), moderate AEs (Levels 5-6), and serious AEs (Levels 7-9). Participants' ratings generated a 5-level hierarchy of global outcomes illustrated in Figure 3.

Conclusion:
After validation, G-PROM will enable randomized controlled trials to report the percentage of patients classified into each level; thus, providing patients and their rheumatologists with a much clearer understanding of the range and likelihood of the total effects of competing treatment options on their quality of life.