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Generating Real-World Evidence from the Excellence Network in Rheumatology

Timothy Beukelman, MD, MSCE[1], **Amy Mudano, MPH**[2], **Patrick Stewart**[2], **Shilpa Venkatachalam, PhD**[3], **Fenglong Xie, PhD**[2], **Michael George, MD, MSCE**[4], **Howard Busch, MD**[5], **Priya Reddy, MD**[5], **Kenneth G. Saag, MD, MSc**[6], **Yujie Su, MS**[2], **Jeffrey R. Curtis, MD, MS, MPH**[1,2,6]

[1]Foundation for Advancing Science, Technology, Education, and Research (FASTER), Birmingham, AL, USA

[2]Illumination Health, Hoover AL

[3]Global Healthy Living Foundation (GHLF), Upper Nyack NY

[4]University of Pennsylvania School of Medicine

[5]American Arthritis and Rheumatology Associates (AARA)

[6]University of Alabama at Birmingham, Birmingham AL

Abstract

The Excellence Network in RheumatoloGY (ENRGY) was founded in 2021 and encompasses data from more than 700 private practice rheumatology providers throughout the United States, forming a practice-based research network (PBRN). Electronic health record (EHR) data from participating practices are aggregated, including structured data (e.g., clinical assessments) and unstructured data from two different EHR platforms. Targeted data quality efforts ensure capture of high-quality clinical data and reduce missingness. The ENRGY data warehouse includes linked administrative claims data for commercial and government-provided insurance (31% of patients linked to commercial claims) and patient-generated health data from both in-office and out-of-office settings via a smartphone app as well as biosensor data. ENRGY network membership also provides participating sites access to technology services that enhance patient care. Centralized ethics approval and pre-existing legal agreements along with electronic tools to curate data and contact eligible study participants improves efficiency of multi-center prospective studies. ENRGY data and infrastructure can be employed to identify the highest yield sites for prospective studies; identify patients meeting study eligibility criteria; pre-screen individual patient's willingness to participate in specific studies; centralize study data monitoring; and assist in the conduct of prospective studies. ENRGY data have been used to generate a growing number of scientific publications and may serve as a model for PBRNs in other specialties seeking to harness the potential of data linkages, patient-generated data capture, and centralized study infrastructure for observational and interventional research.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

INTRODUCTION

The Excellence Network in RheumatoloGY (ENRGY) was founded in 2021 as both a real-world data source and a rich ecosystem for prospective real-world evidence generation. ENRGY began as a unique collaboration between researchers at the University of Alabama at Birmingham (UAB); the non-profit Foundation for Advancing Science, Technology Education, and Research (FASTER); the non-profit Global Healthy Living Foundation (GHLF); and Illumination Health, the research and technology arm of Bendcare and its affiliated community rheumatology physician partner organization, doing business as American Arthritis and Rheumatology Associates (AARA), a large “super-group” of community rheumatology practices. ENRGY is a national practice-based research network (PBRN) with data derived from more than 700 currently active private practice rheumatology providers throughout the United States (US). ENRGY was principally devised to facilitate multi-site prospective observational and interventional studies, although its infrastructure enables high-quality retrospective studies as well. This report provides details of ENRGY to encourage the adoption of similar PBRNs in other medical specialities and to foster new ENRGY-related collaborations.

DESCRIPTION OF THE DATA SOURCES

Rheumatology Provider Electronic Health Records

The foundation of the ENRGY data warehouse is the electronic health records (EHR) data warehouse of participating community rheumatologists throughout the US (Figure 1). All members of ENRGY use one of two EHR platforms that share all of the features described herein, and by the end of 2024 all providers will be using a single EHR platform. Although the beginning of available EHR data varies by individual practice, most extend back to 2015–2017.

Standardized clinical assessments and disease activity measures performed by providers are collected using both disease-specific and disease-agnostic instruments based on a pre-defined schedule. Practices are incentivized to consistently collect data through the US Centers for Medicare and Medicaid Services (CMS) Merit-Based Incentive Payment System and via a network-specific program, the ENRGY Data Quality (EDQ) program. EDQ program participation requires capture of high-quality clinical data and disease activity measures with minimal missingness. Quality checks are performed regularly to ensure required assessments are captured at each visit. Providers and their staff are encouraged to self-monitor their data quality performance using data visualization dashboards, currently a work in progress. The EDQ program also requires providers implement a customizable tablet computer-based system to obtain patient reported outcomes (PROs) at all clinical encounters.

Medication information, laboratory results, and radiology reports are available in EHR data. The EHR contains uniform collection of medications prescribed by both rheumatology providers and primary care providers and other specialists. Use of the tablet app enables patients to confirm the medications that they are currently taking as well as medications they have taken in the past (i.e., medication reconciliation (1)). Structured medication

reconciliation data can serve as a powerful complement to EHR-based medication prescription records to form a more complete and accurate history of medication use (2). Laboratory result data from large commercial lab vendors and specialized labs feed into the EHR, and results are available for approximately 79% of patients (3). While raw diagnostic image data are not currently available, unstructured report information is accessible using manual review by trained abstractors or automated methods incorporating optical character recognition coupled with natural language processing (NLP), text mining, or artificial intelligence (AI) methods. For example, interstitial lung disease can be identified using these methods (4).

Assessments of ENRGY data integrity are regularly performed, focusing on selective monitoring of key data elements. Real-time EHR data are available with no lag (i.e., nightly refresh). Every three months the EHR database is locked to create static datasets for reproducible analyses. EHR data are extracted, transformed, and loaded (ETL) using the Patient-Centered Clinical Research Network (PCORnet) common data model (CDM) (5). As part of the weekly ETL process, derived variables are created to produce clean and normalized data. EHR data are also being transformed to the Observational Medical Outcomes Partnership (OMOP) CDM, enabling use of an even wider-range of tools to support data cleaning, integrity, and analysis (6).

Administrative Claims Data Linkage

Linkage of the ENRGY EHR data to administrative claims data has been accomplished for a large subset of patients. CMS provides health insurance through Medicare for essentially all persons aged 65 years and older and some younger patients who meet specific disability requirements. Linkage to Medicare data is performed using the unique Medicare Beneficiary Identifier (MBI) using an “honest broker” process (7). To date, 93% of attempted Medicare matches in patients aged 65 years and older have been successful (N=264,347 total). Linkage to commercial claims data (Komodo Health) is accomplished using combinations of non-unique identifiers and privacy-preserving record linkage methods with honest broker tokenization via a commercial software vendor (Datavant, the preferred vendor for PCORnet) (8, 9) and performed by a third-party honest broker (FASTER). Additional verification steps are taken following linkage to confirm and verify the linkage and avoid false-positive matches, which otherwise may occur at a rate as high as 5–10% (10). Approximately 50% of patients < 65 years old can currently be successfully linked to closed commercial claims data (i.e., all claims) and approximately 90% to open commercial claims data (i.e., a subset of all claims). Tokenized linkages to claims data produce a single de-identified dataset that satisfies non-human subjects research requirements, facilitating ease of subsequent use. The linkage process is refreshed annually (Medicare) or quarterly (commercial claims data).

Patients

Table 1 shows the characteristics of the more than 1.2 million patients with ENRGY EHR data available from 1,107 providers at 210 rheumatology practices. The median duration of EHR observation is 1.3 years, and 25% of patients have 3.9 years or more of observation available. The South Region (which includes Texas and Florida) is over-

represented compared to the US population (65% versus 38%) (11). Rheumatoid arthritis is the most frequent autoimmune condition (approximately 260,000 patients). Patients with rheumatoid arthritis have a median of 3.1 years of observation available and approximately one-half of these patients have observed use of biologic agents. More than 380,000 patients have been linked to their commercial claims data (Table 1). Recognizing that many patients may be evaluated only once to exclude rheumatology diagnoses or for conditions that do not necessarily require on-going specialist care, approximately 68% of the linked patients have at least 1 month of overlap between available EHR and commercial claims data, and the median duration of overlap in these patients is 1.3 years (interquartile range 0.5, 2.9 years).

In-Office Patient-Reported Outcomes

PROs are collected from patients at ENRGY practices. Between one-third and one-half of ENRGY provider offices regularly use the tablet-based system, with growing participation over time. As a routine part of clinic check-in, patients receive tablet computers loaded with questions and PRO instruments customized to their specific diagnoses, treatment characteristics, or eligibility for study participation. Physicians can then review the PRO results with patients during the office visit from within a PRO dashboard embedded within the EHR. In addition to rheumatology-specific disease activity measures, PROMIS short forms and computer adaptive testing instruments are available for use via this system, with the ability to deliver study-specific instruments for patients in prospective observational or interventional studies in a targeted fashion. A list of the patient-derived measures and the percentage of eligible patients with at least one measurement is shown in Table 2.

Remote Patient-Reported Outcomes Data Capture

In addition to PRO collection at the point of care, simple PROs and other patient-derived information can also be collected using internet-based survey software (e.g., Qualtrics) or electronic data capture options (e.g., REDCap app-based or text messaging-based data capture). For more sophisticated data collection from patients in out-of-office settings, a longstanding partnership with GHLF enables PROs to be collected remotely between clinic visits using a mobile phone app, PatientSpot (formerly known as ArthritisPower). PatientSpot (https://patientspot.org/) has facilitated more than 70 published research studies conducted by more than 30 clinical researchers (12–14). Patients may be recruited to use PatientSpot either through GHLF's flagship patient community CreakyJoints (https://creakyjoints.org/) or by ENRGY providers, who explain the app and encourage them to install it on their phones. Alternatively, recruitment and onboarding can be centralized and completed remotely. PatientSpot PRO responses are directly loaded to the ENRGY data warehouse and made available within the embedded app within the EHR, the same as for in-office PRO collection. The research team can program the app with custom workflows to ask specific questions at pre-defined intervals as part of a prospective research study.

Remote PRO data capture can also be used to participate in Remote Therapeutic Monitoring (RTM), the practice of using a medical device to remotely assess automatically recorded or patient-reported data, including current symptoms and adherence to the treatment plan. In 2022, CMS began a payment program for healthcare providers to incentivize use of RTM, no longer requiring a medical device (e.g., a wearable biosensor) but rather, to

allow software as a medical device. Potential RTM use cases include improving primary and secondary medication adherence, better control disease activity through optimized triage of follow-up visits, and improved patient-provider-staff communications, promoting patient satisfaction. After physicians identify suitable patients and order RTM from the EHR, patients can remotely provide data about medication use and adherence, PROs, and participant health concerns including disease activity and flares of disease through the PatientSpot smartphone app.

Biosensor Data

Biosensor data collected from wearable technology (e.g., fitness tracker wristwatches) has been successfully used to monitor and improve patients' physical activity levels, as well as estimate disease activity levels in patients with arthritis (15). Research study participants can share their wearable biosensor data directly with the PatientSpot app using direct device integration, third-party platforms (e.g., Fitabase), or via health-related data frameworks (e.g., Apple Health, Google Fit). Biosensor data can then be linked to other data in the ENRGY data warehouse for further analysis.

Currently, the PatientSpot app, RTM, and biosensor data collection are deployed only in the context of specific research or quality improvement projects, but widespread deployment is possible.

Additional EHR Data

The OneFlorida+ Partner Engagement Network is one of 8 PCORnet Clinical Research Networks. It consolidates EHR data using the PCORnet CDM in Florida, Alabama (UAB), Georgia (Emory University), and nationally (ENRGY) (16). Because ENRGY data (through Illumination Health) is part of the OneFlorida+ partners (17), opportunities to link to non-rheumatology EHR data (e.g., from primary care physicians or non-rheumatologist sub-specialists) is simplified. OneFlorida+ data not linked to ENRGY can also be used to generate EHR-based comparator cohorts of similar patients without rheumatic disease or to assess common musculoskeletal conditions that may not necessarily be managed by a rheumatologist (e.g., osteoporosis, osteoarthritis, gout). AI-assisted assessment of patients referred for suspected rheumatic diseases could be conducted to optimize referral wait times to ENRGY providers (18).

Biosamples

Biosamples for basic science investigations have been successfully collected in participants enrolled in prospective studies and trials at the time of new medication initiation or vaccine booster administration (19). Future aims are to create a standing biosample repository and to develop real-time EHR notifications when selected patients meet study inclusion criteria to facilitate timely enrolment and biosample collection at scale.

RESEARCH CAPACITIES ENABLED BY ENRGY MEMBERSHIP

Sites participating in the ENRGY network can choose to share all structured and unstructured data in the EHR, which is de-identified in the course of use, as appropriate.

Depending on the need for identifiable data by parties conducting or facilitating research, collaborating entities or institutions sign nondisclosure agreements, business associate agreements (BAA), and data use agreements (DUA) with the network. Approximately one-half of the ENRGY sites participate through this BAA/DUA mechanism to share all their data, as a single BAA/DUA covers all AARA sites. The remaining ENRGY sites routinely share only structured, de-identified data. ENRGY membership is open to any interested provider, although the greatest benefits are realized through sharing EHR data to facilitate the EDQ program and research capacities.

ENRGY data enables foundational capacities for conducting clinical research and implementation science studies and improving quality of care via: (1) identification of the highest yield sites for participation in prospective research studies; (2) identification of individual patients meeting study eligibility criteria; (3) pre-screening of individual patient's willingness to participate in specific studies; (4) centralized study data monitoring from a single location; and (5) assistance in the conduct of prospective studies with functions similar to, but exceeding most clinical research organizations. As non-research capacities, ENRGY network membership also provides access to technology services that enhance patient care, including business analytics tools to optimize patient scheduling, facilitate prior authorization requests for expensive therapeutics, and access to the aforementioned smartphone app-based RTM program.

EXAMPLES OF ENRGY USE CASES AND PRACTICAL RESEARCH TOOLS

Embedded Clinical Trials

Selected ENRGY sites are participating in a randomized platform trial (the COvid VaccinE Response Trial (COVER)) under a master protocol to assess the safety and effectiveness of mRNA COVID-19 booster vaccination in patients with inflammatory arthritis receiving immunosuppressant therapies (19). Patients are randomized to either continue regular dosing of their immunosuppressant therapies or to briefly discontinue them for two weeks at the time of the booster vaccination. The study outcomes are vaccine immunogenicity and disease flare (20). Several aspects of ENRGY infrastructure increased the efficiency of this trial, including: identifying sites with the best capacity and desire to participate; central ethics review board for all clinical sites, with most ENRGY practices considered as a single site with separate performance locations; and texting and calling identified eligible participants to initially recruit them and remind them about follow-up study visits. Remote smartphone-based data collection was used to confirm exposure status, obtain an image of patients' COVID vaccination record, and collect symptoms of arthritis disease flare and COVID infection.

Digital Triage for Newly Referred Patients

Efficient triage to identify patients with more worrisome symptoms and medical history to expedite new referrals can be beneficial. To aid in this, a digital health quality improvement project uses an electronic screening questionnaire to differentiate inflammatory back pain (e.g., ankylosing spondylitis (AS)) from typical mechanical low back pain to patients newly referred for back pain to ENRGY practices. When patients' responses to the questionnaire

are sufficiently suggestive of inflammatory back pain, their appointments are prioritized and optimized. Willing patients newly referred for back pain have their information obtained during the digital data capture process is used to create a draft version of the physician encounter note using large language models that can be verified and modified when the actual office visit occurs. An ultimate goal is to provide a digital infrastructure to test various algorithms to optimize referrals and associated processes for patients with suspected inflammatory disease, which for AS still has a mean delay in diagnosis of more than 6 years (21).

Cohort Builder Software

ENRGY EHR data can be queried by non-experts using a web-based, cloud-hosted R Shiny app with a point and click interface to identify patients with certain disease or treatment-based characteristics and execute sample size calculations for study feasibility and clinical site prioritization for prospective studies. The Cohort Builder creates a complete Table 1 format to present groups of interest (e.g., stratified by newly-initiated medications) and can also be used to directly generate downloadable patient cohorts with simple or complex inclusion and exclusion criteria for additional retrospective analyses.

Virtual Recruitment

After patients are identified as potentially eligible for study participation in the data warehouse, they can be screened directly using the in-office tablet app and for those interested to learn more, can be contacted directly via text without human intervention. Study details can be provided and informed consent obtained as appropriate via text and/or telephone calls by remote research staff, relieving pressure on the clinic site to conduct all research during busy clinical visits. Additional data collection may be performed remotely as useful. This process has been used successfully in a fully de-centralized NIH-funded trial using a virtual reality (VR) cognitive behavioral therapy (CBT) intervention for pain management (22). Eligible patients were identified from the EHR, consented remotely, and more than 300 enrolled with excellent retention. All follow-up data were collected and monitored remotely via smartphone app, with no in-person study visits.

Capturing Patient-Reported Medication Adverse Effects and Effectiveness

Structured collection of patient-reported experiences outside of clinical encounters can enhance the timely assessment of medication effectiveness, safety, and tolerance. As a demonstration, participants in PatientSpot were given the opportunity to provide detailed information about the timing of their methotrexate use and real-time reporting of symptoms of nausea and fatigue via a smartphone-based self-controlled study (23). As part of a new project, patients with rheumatoid arthritis are prompted weekly using automated prompts via a smartphone app to report when they first take a newly prescribed medication to assess and address primary non-adherence (2). Because baseline clinical information combined with longitudinal PROs can accurately identify achievement of low disease activity following initiation of new biologic treatment, they could potentially be used to infer treatment effectiveness in research and clinical care settings (24).

Because ENRGY studies are nested within a larger EHR, study participants can be compared to non-responders, and weighting methods can be used to partially mitigate non-response bias (25).

STRENGTHS, LIMITATIONS, AND OTHER CONSIDERATIONS

The primary strengths of the ENRGY network for research arise from the wide diversity of patients in community rheumatology practices, availability of both structured and unstructured EHR data, linkage with multiple other diverse types of data sources, and the low barriers to conducting prospective studies. Enrichments to the rheumatology specialist EHR include structured data fields for clinical assessments and results of medication reconciliation; in-office PROs deployed as part of routine care; linked administrative claims data for commercial and government-provided insurance; and remote PRO collection, including biosensor data. Centralized ethics approval and pre-existing legal arrangements allow quicker implementation of studies and time to activation, and electronic tools allow for more efficient site selection, participant recruitment, and study monitoring.

The primary limitations of ENRGY are its specialist-only EHR and potentially limited generalizability. ENRGY EHR data is restricted to rheumatology practices and information about the clinical care of other non-rheumatology conditions or events (e.g., safety) is incomplete outside of linkages to claims data, other EHR data sources, or prospective ascertainment. There are currently no academic medical centers contributing EHR data to ENRGY; this may impact the characteristics of the patients and the care they receive, although it has been estimated that 88% of rheumatologists in the US are in community practices (26).

DATA ACCESS AND COLLABORATIONS

Data access is only available via collaboration, as ENRGY data are not for sale or license. Limited or de-identified data sets can be made available to investigators for approved research protocols or analyses can be conducted centrally by members of the ENRGY research team.

SUMMARY

In summary, ENRGY is a recently created rheumatology PBRN consisting of multiple data sources including EHR data, lab results, linked administrative claims data, and in-office and remote PRO collection. In addition to possessing rich data for retrospective studies, the close association between researchers and clinical sites, as well as the availability of electronic tools to assess the data and contact potential participants, enable efficient conduct of multi-center prospective studies. ENRGY may serve as a model for PBRNs in other specialties seeking to harness the potential of data linkages, PRO capture, and centralized study infrastructure for research.

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KEY POINTS

- The Excellence Network in RheumatoloGY (ENRGY) aggregates data derived from more than 700 private practice rheumatology providers and their patients throughout the United States forming a practice-based research network (PBRN).
- The ENRGY data warehouse contains electronic health record (EHR) data, linked administrative claims data, and patient reported outcome data from both in-office and remote settings.
- In addition to possessing rich data for retrospective analyses, the close association of clinical sites, as well as the deployment of electronic tools to query the data and contact potential study participants, enables efficient conduct of multi-center prospective studies.

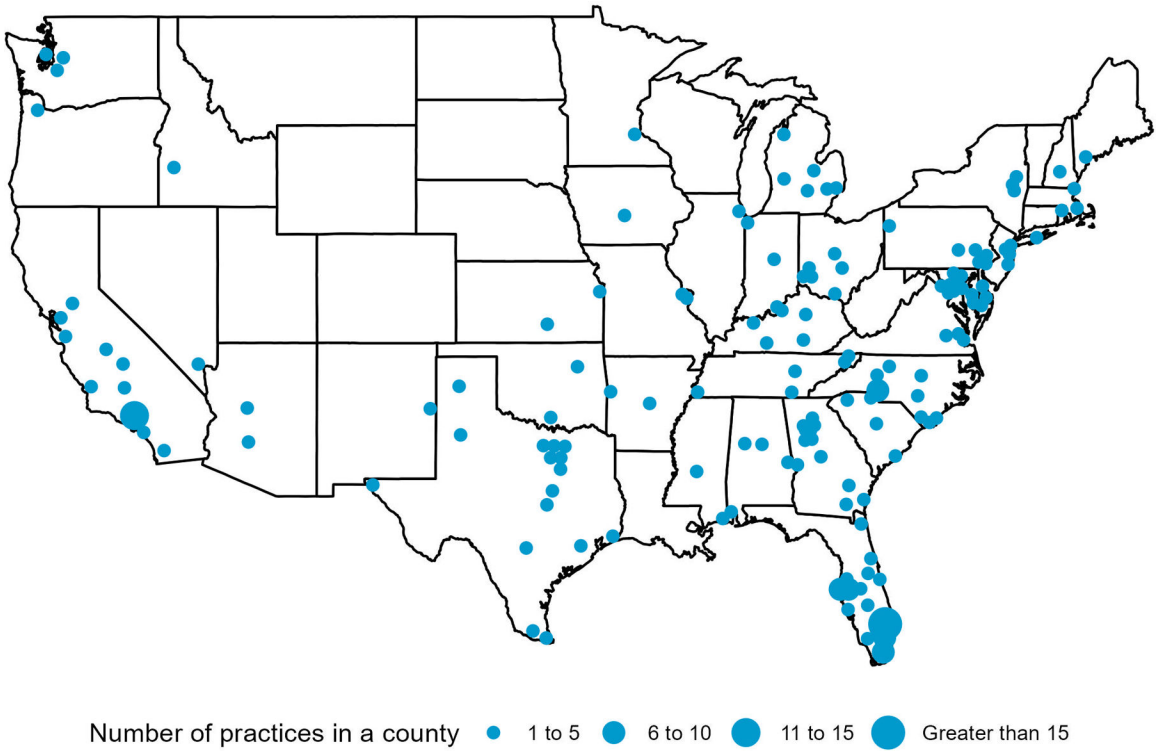

Figure 1.

Location of community rheumatology practices participating in ENRGY throughout the United States. The size of each circle corresponds to the number of participating practices in that county.

Table 1.

Characteristics of patients in ENRGY EHR data from rheumatology practices

Characteristic	All Patients	Patients with Linked Commercial Claims Data
Number of patients (%)	1,235,938 (100%)	381,707 (31%)
Median Age (IQR)	63 (51, 73)	60 (49, 68)
Age (%)		
< 18 years	0.4%	0.3%
≥ 18 and < 65 years	53%	65%
≥ 65 years	46%	35%
Female (%)	76%	76%
Race/Ethnicity (%)		
White	59%	61%
Hispanic	9%	9%
Black	7%	7%
Asian	2%	2%
Other/Unknown	23%	22%
Census Region (%)		
West	12%	8%
Midwest	11%	11%
Northeast	13%	17%
South	65%	64%
Rheumatology Conditions (%)		
Osteoarthritis	34%	33%
Rheumatoid arthritis	21%	23%
Osteoporosis	14%	12%
Psoriatic arthritis	6%	8%
Sjogren syndrome	5%	6%
Systemic lupus erythematosus	5%	6%
Gout	5%	5%
Axial spondyloarthritis	3%	4%
Polymyalgia rheumatica	3%	2%
Years of EHR observation		
Median (IQR)	1.3 (0.3, 3.9)	1.5 (0.3, 4.1)
Mean (SD)	2.5 (3.0)	2.7 (3.1)
Among patients with rheumatoid arthritis *, years of EHR observation		
Median (IQR)	3.1 (1.2, 5.6)	3.1 (1.2, 5.6)
Mean (SD)	3.8 (3.3)	3.8 (3.3)

Characteristic	All Patients	Patients with Linked Commercial Claims Data
Among patients with rheumatoid arthritis *, observed treatment with any biologic agent	51%	54%

* rheumatoid arthritis is an example of a chronic condition that typically requires ongoing care from a rheumatology provider

IQR=interquartile range; SD=standard deviation

Table 2.

Patient-derived measures collected in ENRGY

Measure	Eligible patients* with at least 1 measurement (%)
CDAI (rheumatoid arthritis)	61%
Patient pain scale	32%
Patient global disease activity scale	32%
RAPID3	32%
PROMIS Fatigue	24%
MD-HAQ	21%
PROMIS Pain Interference	18%
PASS	16%
PROMIS Sleep Disturbance	16%
BASDAI (ankylosing spondylitis)	15%
PALMPASS (psoriatic arthritis)	11%
PSAID12 (psoriatic arthritis)	9%
Work-Housing-Food**	9%
Social Network Scale**	4%
Green Spaces**	4%
PROMIS Physical Function	4%
PROMIS Depression	4%
KOOS-12 (osteoarthritis)	4%
ESSPRI (Sjogren syndrome)	4%

* numerator and denominator restricted to patients with the relevant conditions

** measures of social determinants of health

RAPID3=Routine Assessment of Patient Index Data 3; MD-HAQ=multidimensional health assessment questionnaire; PASS=Patient Acceptability Symptom State; PROMIS=Patient Reported Outcomes Measurement Information System; KOOS=Knee injury and Osteoarthritis Outcome Score; BASDAI=Bath Ankylosing Spondylitis Disease Activity Index; ESSPRI=EULAR Sjogren Syndrome Patient Reported Index; PSAID=Psoriatic Arthritis Impact of Disease; PALMPASS=Patient-Administered Limited Measure of Psoriasis Area and Severity Score; CDAI=Clinical Disease Activity Index