Capturing Patient Reported Outcomes in RA To Improve Quality of Care & Outcomes in Real-World Settings

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**PURPOSE**

- **Goal:** To implement practical, real-world tools in routine clinical practice to measure Patient Reported Outcomes (PROs) and RA disease activity.

- **Objectives:**
  - Determine barriers of patients to PRO data capture in routine clinical practice and at home; and b) examine patient perspectives regarding using PROs to resolve discordance in patient-provider assessments as it relates to decision-making in achieving RA treat-to-target (T2T) goals.
  - Capture physician’s perception on what elements of a patient’s history, signs, and symptoms are most helpful in making treatment recommendations for the management of RA.
  - Demonstrate the feasibility and usefulness of electronically capturing patient reported outcome (PRO) data at patients’ homes.
METHODS

• **AIM 1:** RA patients were recruited from one academic medical center to participate in a series of focus groups to identify factors that may influence patient willingness to share data collected electronically.

• **AIM 2:** Rheumatologists were recruited to participate in nominal groups and/or to complete an online survey. The groups documented responses as to what elements of a patient’s history, signs, and symptoms were most helpful in making treatment recommendations for the management of RA. The responses were then categorized into themes.

• **AIM 3:** The beta release of the ArthritisPoWER software application was deployed to approximately 2500 arthritis patients, informed by the output from AIMs 1 and 2, to collect additional and larger scale patient feedback on optimizing PRO data capture.
AIM 1 (patient-focused): The results from the patient focus groups (31 participants) yielded a large volume of qualitative data around the topic of patient willingness to log RA disease activity data for sharing with healthcare providers via Smartphone applications.

Note: 58.1% of participants were “very” or “extremely” comfortable sharing arthritis information with persons outside their healthcare team, 54.8% were very/extremely likely to use electronic or online tools to share RA information, and 64.5% reported that their RA was “high” or “essential/highest” health priority. Extremely = 100%; Very = 75%; Fairly = 50; Only slightly = 25; Not at all = 0%.
AIM 2 (rheumatologist-focused): A total of 25 rheumatologists participated in nominal groups which led to a larger online survey. The elements of greatest concern generated across the groups were categorized into 13 themes and ranked to prioritize what elements of PRO data capture were most important, and most potentially concerning, to physicians.

The aspects of patient data that could be captured between visits (e.g. Smartphone App) that physicians graded as very important.
AIM 3: (Implementation and feedback): A re-launch of the PRO platform, with changes resulting from 255 comments/recommendations from patients regarding user interface experience, data visualization, options for tracking PROs and the medication module has been highly successful and more than 10,000 patients have now joined the registry and are using it to record PROs.
PUBLICATIONS, PRESENTATIONS, PRODUCTS

- **Papers**
  - Aprajita Jagpal, MD, Ronan O’Beirne EdD, Melanie S. et. al. *What is important to the rheumatologists in making treatment decisions for rheumatoid arthritis? A Qualitative Study.* (Under review in Arthritis Care and Research)

- **Presentations**
  - “PROs in Inflammatory Arthritis: Electronic Capture to Improve Patient Outcomes” – Investigators Meeting-Rheumatology Research Foundation, Atlanta, GA. June 2016

- **Abstracts**