

Technology project to analyse thousands of personal experiences of rheumatoid arthritis drugs

October 31 2016, by Joe Paxton

A new type of academic research will investigate treatment and management of rheumatoid arthritis (RA), by using software to analyse thousands of real life experiences of RA drugs.

The research study, launching in November, is being run by three distinct organisations—the social network HealthUnlocked, National Rheumatoid Arthritis Society (NRAS) and The University of Manchester. It will review and assess first hand experiences of drug usage and side-effects from thousands of people living with the condition through conversations, engagement and discussions happening about the condition on [social media](#).

The research will provide helpful insights about potential harms of drugs prescribed by doctors every day and seek to devise new drug safety profiles, by better understanding the occurrence and impact of [adverse drug reactions](#) (ADR) and the context within which they happen. With around 690,000 people affected by [rheumatoid arthritis](#) in the UK alone, this is potentially big news for people with the autoimmune disease.

The data will be collected directly from within the HealthUnlocked web platform. Data and information on side effects will be extracted into an anonymous and aggregated form that can be provided to The University of Manchester. The information will be sourced from a dedicated RA support forum, run by NRAS on the HealthUnlocked web platform,

which has over 13,000 members and over 18,000 posts within it. This data rich information provides accurate accounts of what real people with the condition are going through and their experiences.

The University of Manchester will analyse this data and collate the beneficial and harmful responses of RA medication.

Will Dixon, Professor of Digital Epidemiology at The University of Manchester and a Consultant Rheumatologist at Salford Royal Hospital said: "We are excited to get the opportunity to work with NRAS and HealthUnlocked in order to analyse patients' real experiences. When studying drug safety, it is common to focus on side-effects that doctors consider important, or on newer drugs whilst forgetting the more established treatments.

"We will start by examining the safety of glucocorticoid, or steroid therapy, a drug that has been used for over 65 years and is still used in half of patients with RA. In addition to looking at the occurrence of a range of known side-effects, we are interested in examining the impact of these side-effects on patients' lives. We know, for example, that weight gain and insomnia are of top importance to patients. By studying real world experiences and stories, we can start to understand both the frequency and the nature of drug benefits and side-effects—and what matters to patients."

Dr Matt Jameson Evans, Chief Medical Officer at HealthUnlocked, said: "This is a brand new way of studying a disease, starting from the patient's perspective. By looking at patterns in experiences of people with a condition or disease within a social network, we can access and understand a large mass of data showing what is happening to real people every day.

"Conversations within social media do not conform to usual routine

trials—their discussions rarely use medical terms or concepts to describe their health conditions, and conversations are with peers, which can be dramatically different from those they have with clinicians or researchers. We will be fascinated to see how this data corresponds to existing medical knowledge about rheumatoid arthritis."

Ailsa Bosworth , CEO of NRAS said: "We are very interested to see how using real patient data in this way helps researchers to understand what really matters to people with RA in relation to side effects and impact of taking specific medications, as opposed to using clinical outcome data where the outcome tool has been designed by health professionals. We would like to see more patient defined outcomes starting to be used and this research is exactly what could help that to become a reality."

Provided by University of Manchester

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