medication and treatment thus impeding their ability to achieve the best outcomes. We know, for example, that many people do not take their medication as prescribed which reduces their chances of achieving remission or low disease activity state.

Objectives: To demonstrate that by referring patients online as part of a quality improvement programme to NRAS Right Start Service, we can show improved outcomes for patients with early RA when measured by the MSKHQ. Referred patients will benefit by: a) Better understanding what RA is; b) knowing how it can affect them; c) getting the right support; d) feeling more in control; receiving a tailored pack of information that meets their personal needs; e) be able to talk to a like-minded person who has lived with RA. It's a 4 step process which starts with the health professional referring their patient to NRAS on line. NICE Quality Standard 3 states that "Adults with rheumatoid arthritis are given opportunities throughout the course of their disease to take part in educational activities that support self-management." Our service enables health professionals to meet their responsibilities against this national quality standard.

Methods: In preparation for the introduction of this service at BSR congress 2019, an audit of the NRAS helpline service was undertaken at the end of 2018 and remains on going. Currently we have 224 responses which have been analysed against specific criteria. An Advisory Board comprising 7 clinicians, from different hospitals was appointed to work with NRAS on this important research.

Results: In the helpline audit, when asked 'how concerned are you about your disease?', alarmingly, 78% of those surveyed scored their level of concern about their disease at 7 or higher out of 10, while only 8% scored it at 5 or below. When asked about the emotional effects of their RA, 62% scored it as 7 or more where 10 was the worst possible impact. 94% of survey respondents said that they would definitely or very likely recommend NRAS and its services to another person. These results led to the development of New2RA Right Start launched in 2019, whereby health professionals across the UK can refer their patients directly to NRAS via a consented online referral which is fully GDPR compliant. To date (31st Jan, 2020), we have made calls to 101 patients, from 24 referring hospitals of which 55 have been successfully completed, 34 have had information sent through the post although our helpline team were unable to speak to them, and 12 remain open. Data analysis on the service is being carried out by King's College Hospital London, comparing the results of patients who have been referred to Right Start within the national audit who have completed a baseline and 3 month follow up MSKHQ and patients in the audit who have not participated in Right Start.

Conclusion: Anecdotal, we have had a tremendous response to this service from both patients and referring health professionals. We await data from King's on the above figures, which we will have within the next 2 months and further data, should this abstract be accepted, will be available prior to June 2020. Right Start enables health professionals to comply with QS3 above, of the NICE Quality Standards in RA, one of the key standards against which they are being audited in the NEIAA national audit. Once data and write up in a peer review journal has been published we plan to roll this service out to people with more established disease.

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[1] To be done, not included in word count.

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SATURDAY, 06 JUNE 2020

Work and rehabilitation

PARE0006

WORK PRODUCTIVITY LOSS IN PATIENTS WITH INFLAMMATORY ARTHRITIS

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Background: Limited data exist of work productivity loss in patients with Rheumatoid Arthritis (RA), Psoriatic Arthritis (PsA) and Spondyloarthritis (axSpA).

Objectives: The objective of this research was to assess productivity loss and absenteeism in patients with RA, PsA and axSpA.

Methods: The study was designed as a cross-sectional study aimed to collect patient-reported outcomes from patients with RA, PsA and axSpA in Denmark via a nurse administered questionnaires and patient journals. Patients ≥18 years with RA, PsA or axSpA were consecutively recruited for the study over a 6-month period via routine visits to outpatient rheumatology clinics. Descriptive statistics were analyzed using SAS.

Results: Of 488 respondents, 62% were women and mean age was 53.5 years (RA:57.4; PsA:52.6; axSpA:43.6). Average time since diagnosis was 11-15 years, however, for PsA and axSpA most patients answered 6-10 and 0-5 years, respectively. 280 (57%) answered that they had a job and completed the WPAI questionnaire (RA: 149 (51%); PsA: 48 (56%); axSpA: 83 (75%)). Average work hours was 31.9 in the last week (RA:31.2; PsA:33; axSpA:32.4). Average missed work hours were 4.3 in the last 7 days ((RA:4.0; PsA:4.2; axSpA:4.8), of which 32% was missed due to their inflammatory arthritis (RA:30%; PsA:38%; axSpA:32%). Mean absenteeism was highest for patients with PsA (mean=6.8; SD=17.7) followed by patients with axSpA (mean=5.4; SD=15.1) and with RA (mean=3.4; SD=12.2). Mean productivity loss was 20.5 (SD=23.8) for patients with RA, 27.6 (SD=25.8) for PsA and 26.3 (SD=25.8) for axSpA

Conclusion: We found that patients with PsA or axSpA miss more hours of work compared with patients with RA and when they are at work they have a higher absenteeism/lower productivity. This even though that both the group of patients with PsA and the axSpA were younger and had lived less time with their diagnosed disease compared with the group with RA.

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RMD research

PARE0007

PATIENT AND PUBLIC INVOLVEMENT IN CLINICAL TRIAL DESIGN

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Background: Patient and public involvement (PPI) is gaining increasing recognition as important in ensuring research is relevant and acceptable to participants. Rheuma Tolerance for Cure (RTCure) is a 5 year international collaboration between academia and industry; focusing on earlier detection and prevention of rheumatoid arthritis (RA) through the use of immune-tolerising treatments.

Objectives: To bring lived experience and insight into scientific discussions; and to evolve collaboration between lay representatives and academia/industry.

Methods: 9 Patient Research Partners (PRPs) from 5 European countries were recruited via the EULAR PARE Network and institutions within the RTCure Consortium (8 PRPs with RA and 1 'at risk'). They were asked to enter into a legal agreement with the Consortium. PRPs participated in teleconferences (TCs) and were invited to attend face-to-face (F2F) meetings at least annually. Requests for input/feedback were sent from researchers to PRPs via the project's Patient Engagement Expert [SK].

Results: PRP involvement has given researchers and industry partners a new perspective on patient priorities, and focused thought on the ethics of recruitment for

and participation in clinical trials of people 'at risk' of developing RA. PRPs have helped define the target populations, given their thoughts on what types of treatments are acceptable to people 'at risk' and have aided the development of a survey (sent to EULAR PARE members) regarding the use of animal models in biomedical research. Positive informal feedback has been received from researchers and industry regarding the contribution of PRPs to the ongoing project (formal evaluation of PPI in RTCure will be carried out in 2020 and at the project end in 2022).

Challenges: *Legal agreements* - Many PRPs refused to sign the Consortium's complex PRP Agreement; feeling it unnecessary, incomprehensible and inequitable. After extensive consultation with various parties (including EULAR and the Innovative Medicines Initiative) no similar contract was found. Views for its requirement even varied between legal experts. After 2 years of intense discussion, a simple non-disclosure agreement was agreed upon. Ideally any contract, if required, should be approved prior to project onset.

Meeting logistics - Other improvements identified were to locate the meeting venue and accommodation on the same site to minimise travel, and to make it easier for PRPs to take breaks when required. This also facilitates informal discussions and patient inclusivity. We now have agreed a policy to fund PRPs extra nights before and after meetings, and to bring a carer if needed.

Enabling understanding - Future annual meetings will start with a F2F meeting between PRPs and Work Package Leads. Researchers will be encouraged to start presentations with a summary slide in lay language. Additionally, an RTCure Glossary is in development.

Enabling participation - SK will provide monthly project updates and PRP TCs will be held in the evening (as some PRPs remain employed). PRPs will be invited to all project TCs and F2F meetings. Recruitment is underway to increase the number of 'at risk' PRPs as their viewpoint is vital to this study.

Conclusion: Currently PPI in RTCure is an ongoing mutual learning process. Universal guidance regarding what types of contracts are needed for PPI would be useful. Communication, trust and fruitful discussions have evolved through F2F meetings (both formal and informal) between PRPs, academia and industry. It is important that all parties can be open with each other in order to make PPI more meaningful.

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SATURDAY, 06 JUNE 2020

Involvement and innovation in healthcare

PARE0008 MOBILE APPLICATION "MOJRA" FOR MONITORING PATIENTS WITH RHEUMATOID ARTHRITIS

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Background: In Serbia, regular examinations with a rheumatologist are scheduled on average every 3 to 4 months. With this in mind, there is a real possibility that many patient data during this period may not be presented to the doctor during the examination, either because the patient forgets them or because they may focus on other issues and may not highlight key facts

Objectives: To overcome this problem, the Association of Patients with Rheumatic Diseases of Serbia-ORS in cooperation with an IT firm developed the application "MojRA" which was presented at the annual rheumatology congress of Serbia held in September 2019. The application "MojRA" is intended for patients suffering from rheumatoid arthritis - RA. The application enables efficient storage and systematization of data, allows doctors to monitor the condition of their patients between two examinations and have a medical history. "MojRA" is available for now from smartphones running the android operating system on the google play store. The privacy of patient information is guaranteed.

Methods: Patients with RA will be able to record and store information about important moments during treatment in a simple and transparent way. At each subsequent visit they will be able to describe what happened to their illness in the meantime. The application can create different types of reports and views. At the same time, the doctor can use the app to inform the patient about her/his condition in real time, which will contribute to better and more meaningful

communication. All this would improve the quality of health care, preserving work capacity and improving the quality of life.

Results: In order to simplify biotherapy committee approval procedure for patients of RA, the "Charger" has been developed in association with ORS and URes. The "Charger" will connect data collected by MojRA to the registry of RA patients, making the whole approval procedure more efficient and transparent. Testing of the second version of this application is underway, meetings are held between the patients using the application and the IT company that created it. Plans are to expand the app to other types of arthritis in the near future, too, and will soon be completed for devices running Apple operating systems.

Conclusion: In addition to being of great benefit to patients and doctors, it can in the future be of immeasurable importance for the savings in the overall health care system of the Republic of Serbia.

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PARE0009 COMMUNITY ADVISORY BOARD INPUT CAN MAKE LAY SUMMARIES OF CLINICAL TRIAL RESULTS MORE UNDERSTANDABLE

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Background: Under European Union (EU) Clinical Trial regulations,¹ clinical research sponsors (CRSs) must ensure all studies performed in the EU are accompanied by a trial summary for laypersons, published within 1 year of study completion. These lay summaries should disseminate clinical trial results in an easy-to-understand way for trial participants, patient and caregiver communities, and the general public. The European Patients Forum (EPF)² and European Patients' Academy on Therapeutic Innovation (EUPATI)³ encourage CRSs to engage with patient organisations (POs) in the development of lay summaries. This recognises the patients' contribution to clinical research and supports the development of patient-focused material.

Objectives: We share learnings from a collaboration between scleroderma POs and a CRS to create the SENSICIS® trial (NCT02597933) written and video lay summaries.

Methods: A community advisory board (CAB), comprising representatives from 11 scleroderma POs covering a range of countries/regions, was formed based on the EUORDIS charter for collaboration in clinical research.⁴ Through three structured meetings, over a seven-month period, the CAB provided advice on lay summary materials (written and video) drafted by the CRS' Lay Summary Group (Fig. 1). At each review cycle, the CAB advice was addressed to make content more understandable and more relevant for patients and the general public.

Results: The CAB advised that the existence of lay summaries is not well known in the patient community and also recommended the development of trial-specific lay summary videos to further improve understandability of the clinical trial results for the general public. Videos are a key channel of communication, enabling access to information for people with specific health needs and lower literacy levels. Following CAB advice, the CRS developed a stand-alone video entitled "What are lay summaries?" and a trial-specific lay summary video. Revisions to lay summary content (written and video) included colour schemes, iconography and language changes to make content more understandable. For videos, adjustments to animation speed, script and voiceover were implemented to improve clarity and flow of information (Fig. 2). Approved final versions of lay summary materials are publicly available on the CRS website. Translation into languages representing trial-site countries is in progress to widen access to non-English speakers and, where possible, local versions are being reviewed by the patient community.