

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.

Acknowledgments: This work has received support from the EU/EFPIA Innovative Medicines Initiative 2 Joint Undertaking RTCure grant number 777357.

Disclosure of Interests: Savia de Souza: None declared, Ruth Williams: None declared, Eva Johansson: None declared, Codruta Zabalán: None declared, Tom Esterine: None declared, Margôt Bakkers: None declared, Wolfgang Roth: None declared, Neil Mc Carthy: None declared, Meryll Blake: None declared, Susanne Karlfeldt: None declared, Martina Johannesson: None declared, Karim Raza Grant/research support from: KR has received research funding from AbbVie and Pfizer, Consultant of: KR has received honoraria and/or consultancy fees from AbbVie, Sanofi, Lilly, Bristol-Myers Squibb, UCB, Pfizer, Janssen and Roche Chugai, Speakers bureau: KR has received honoraria and/or consultancy fees from AbbVie, Sanofi, Lilly, Bristol-Myers Squibb, UCB, Pfizer, Janssen and Roche Chugai
DOI: 10.1136/annrheumdis-2020-eular.145

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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Disclosure of Interests: None declared

DOI: 10.1136/annrheumdis-2020-eular.3922

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 SENSCIS® 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.