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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Involvement and innovation in healthcare

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

N. Teodorovic[1], S. Djordjevic[1], L. Vranic[1]. [1]*Belgrade, Belgrade, Serbia*

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

J. Welling[1], A. Roennow[1,2], M. Sauvé[3], E. Brown[4], I. Galetti[1,5], A. Gonzalez[6], A. P. Portales Guiraud[7], A. Kennedy[1], C. Leite[8], R. J. Riggs[9], A. Zheng[10], M. Perkovic Popovic[11], A. Gilbert[12], L. Moros[12], K. Sroka-Saidi[13], T. Schindler[12], H. Finnern[12]. [1]*Federation of European Scleroderma Associations aisbl. (FESCA), Saint Maur, Belgium*; [2]*Sklerodermiforeningen, Rødovre, Denmark*; [3]*Scleroderma Canada, Hamilton, Canada*; [4]*Scleroderma and Raynaud's UK, London, United Kingdom*; [5]*Gruppo Italiano per la Lotta alla Sclerodermia, Milan, Italy*; [6]*Scleroderma Research Foundation, San Francisco, United States of America*; [7]*Asociación Española de Esclerodermia, Madrid, Spain*; [8]*Associação Portuguesa de Doentes com Esclerodermia, Matosinhos, Portugal*; [9]*Scleroderma Foundation, Danvers, United States of America*; [10]*Chinese Organization for Scleroderma, Chengdu, China*; [11]*Croatian Society for Patients with Scleroderma, Zagreb, Croatia*; [12]*Boehringer Ingelheim International GmbH, Patient Advocacy Relations, Ingelheim am Rhein, Germany*; [13]*Boehringer Ingelheim Pharma GmbH & Co. KG, Biberach an der Riß, Germany*

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 EURORDIS 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.

Conclusion: Structured collection and implementation of CAB advice can make lay summary materials more understandable for the patient community and wider general public.

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Fig. 1. Summary of iterative process to gather and collate CAB advice to make lay summary materials more understandable

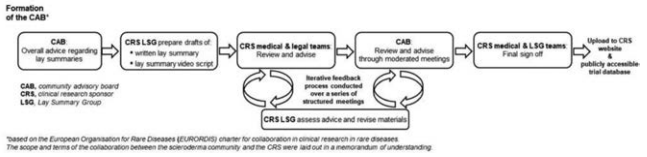
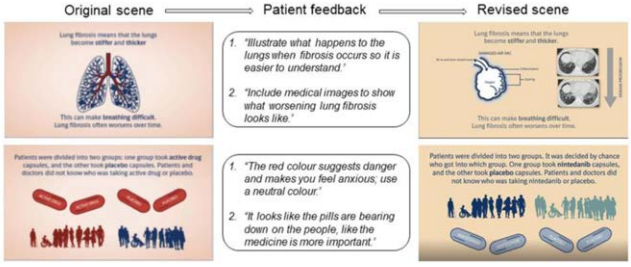


Fig. 2. Examples of revisions to the trial-specific lay summary video made in response to CAB advice



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PARE0010 THE VR DOCTOR – THE IDEAL DOCTOR'S APPOINTMENT

C. Helin Hollstrand[1], K. Nilke Nordlund[1]. [1]*The Swedish National Organization for Young Rheumatics, Stockholm, Sweden*

Background: With new technology available, health care is evolving quickly, and new solutions are constantly being presented. Although few of these solutions focus on patient-participation and patient empowerment. That's what we wanted to create! Using virtual reality, we figured we could prepare and empower patients before meeting their doctor – and also giving doctor's a chance to see what it's like sitting across the table.

Objectives: The main objective was to show an example of how an ideal visit to the doctor could look like, to empower patients. By knowing their rights and what kind of care they are entitled to, we wanted to make patients more prepared and feel safer and more comfortable before a doctor's appointment. The experienced is based on the Swedish Patient Act. We also wanted to be able to show health care professionals what it's like being a patient, and giving them the opportunity to try it out.

Methods: We teamed up with fellow patient organizations Proud Bellies (Stolta Magar) and Youth with Psoriasis (Ung med Psoriasis), pharmaceutical company AbbVie and e-health company Cambio to create the virtual reality experience. Together we workshopped what the ideal doctor's appointment would be like, based on the Swedish Patient Act, and wrote the script. Our example doctor's visit is generic, meaning all of our three organizations could use it even though we represent different diseases and diagnoses. But we also created three other virtual reality experiences. They are disease specific, and one is for RA. In the film, you get to go inside the joint to see what happens when you have rheumatism, while a speaker explains it to you.

Results: We launched the VR Doctor in January of 2019 with a great event. Patients, health care professionals, press and others were gathered and got to try a visit to the VR Doctor. It was very-well received, especially by other patients. Since then, we have used the tool during our member activities such as summer camps, to empower our members. And we have introduced the tool for health care professionals at several rheumatology clinics throughout Sweden.

Conclusion: With new technology comes great opportunities to simplify complicated matters. The VR Doctor is essentially a crash course in the Swedish Patient Act, making it a very useful tool for both patients and health care professionals. By giving an example of what an ideal doctor's appointment could be like, we are letting patients take matters into their own hands and bringing them a sense a power and control over a situation that normally could be tough and sometimes intimidating. With empowered patients who feel safe, we are one step closer full patient-participation and in the long run a better health care system for all.

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Work and rehabilitation

PARE0011 AFLAR'S (FRENCH LEAGUE AGAINST RHEUMATISM) NEW ACTIONS TO HELP PEOPLE WITH RHEUMATIC DISEASES TO GET AND STAY EMPLOYED.

L. Carton[1,2], L. Grange[2], F. Alliot Launois[2], G. Chales[2], B. Liesse[2], C. Jandard[2]. [1]*Paris, Paris, France*; [2]*AFLAR, Paris, France*

Background: Accessing jobs and being able to stay in a paid work position are a personal issue for people with rheumatic diseases, as well as for society. AFLAR, French league against rheumatism, has been acting towards patients and employers since 2014 in this field.

Objectives: After a preparatory work with a panel of all types of professionals and institutions working on the subject, key messages on means to improve the professional situation of people with rheumatic diseases have been published. These messages were used as a basis for an awareness training designed for human resources training and employers' managers, and in a guidance booklet designed for patients and published in 2016: «At work, even if affected by chronic rheumatic diseases ». This booklet, rather than gathering administrative and social resources in favour of patients, was based on patients' and experts' expression, written with them and proposed gradual guidance along their path from their professional choices to the disabled worker certification when needed. Two new actions have been seen as necessary in 2019 in order to go on with our actions: updating our booklet after 2 new laws had been issued in the field of labour law, and additions seemed necessary because of new work methods are developing (distant work from home, independent work); and the need of a new widely spreadable tool to accompany patients from the diagnosis stage, especially on the diagnosis disclosure to the work group issue.

The specific characteristics of rheumatic diseases: diversity, growing invisibility of diseases' effects and aftereffects to new treatments such as biologics and early rehabilitation, variation in time and personal impact, make them hard to understand by employers and even untrained social workers. This is what we noted from our experience in patient education workshops. Patients have a tendency to hide their pathology, and thus cannot benefit from social advantages as disabled workers, with motivation based on keeping personal image and an idea of normality, and fear of negative reactions from the work group, such as depreciation, pity, idea of negative impact on team's productivity).

Patients have to build a real strategy, taking into account these criteria and their personal choices, while preparing their job's adaptation or social requests when needed. AFLAR chose to create a new patient information tool: free short widely spreadable videos, available on line. These will also invite patients to get in touch with expert patients on the specialized hotline, participate to chats of patient education workshops.

Methods: Videos will show witness patients and experts, who will be asked about their experience and advice based on four questions: