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

References:

- [1] EU. Summaries of clinical trial results for laypersons. 2018
- [2] EPF. EPF position: clinical trial results – communication of the lay summary. 2015
- [3] EUPATI. Guidance for patient involvement in ethical review of clinical trials. 2018
- [4] EURORDIS. Charter for Collaboration in Clinical Research in Rare Diseases. 2009

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

*Based on the European Organisation for Rare Diseases (EURORDIS) charter for collaboration in clinical research in rare diseases. The scope and terms of the collaboration between the scleroderma community and the CRIS were laid out in a memorandum of understanding.

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

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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 workshoped 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 of 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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SATURDAY, 06 JUNE 2020

Work and rehabilitation

PARE0011

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

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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:

- Should we speak about our disease (and when, how?), or not speak about our disease at work?

- What means « disablement », « being disabled » for you as a person affected by a rheumatic disease?

- What have you been able to do to get a paid position, or keep your job, that you could quote as an advice for other people in the same situation?

- If you had been given, or were given now a magic wand to make it easier to get or keep a job, or get/keep the job you dreamed of, what would you change?

At the end, videos will deliver further advice, tools and resources taken from the booklet, such as a model of decisional scale, or reference institutional website addresses.

Results: AFLAR wishes to contribute actively to rheumatic patients', and especially young people's information on the topic thanks to these more innovative and interactive tools.

Conclusion: Furthermore, wishes, solutions and ideas of witness patients and users will be gathered for advocacy towards employers, institutions and decision makers.

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Campaigning

PARE0012 AWARENESS CAMPAING "LUPUS.GR 2020"

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Background: LUPUS GR 2020

Objectives: To sensitize and educate the wide public about lupus To contribute to the process of de-stigmatization as the rigid problem of prejudice and stigma prevails.

Methods: The campaign "LUPUS GR 2020" consists of photographs, each of which has a different message for Lupus and 2 TV spots. The well know artists participated did not take any fee.

The campaign consists of

Press Announcements in digital and off digital media, in Social Media (Instagram - Twitter - Facebook), in Eleana Site and in YouTube

Post of the artists in their personal social media pages

Press Conference

Direct mail in international NGOs e.g. Lupus Europe, PAIN ALLIANCE EUROPE, AGORA PLATFORM, etc.

Results: We announced the campaign on January 24, 2020. Until end of January, we have 36 press clipping, 3 TV interviews, more than 35.000 views of the post in our fb and increase of telephone calls in our help line about lupus

Conclusion: The campaign has a high impact in the wide public as well as in all the stakeholders.

Figure:

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Patient information and education

PARE0013 'FIND A NUDGE' AND OTHER TIPS TO MAINTAIN YOUR LEVEL OF PHYSICAL ACTIVITY FOR A LONGER TIME

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Background: Pain, fatigue, physical disability, reduced well-being and sleep problems are common consequences of Rheumatic and Musculoskeletal Diseases (RMDs). Paradoxically, these consequences may all lead to a reduction of physical activity, while physical activity actually is an antidote against these consequences. This is acknowledged by experts that included physical activity and exercise into recommendations for management of RMDs [1-3]. Indeed, after programs aimed at a gradual build-up of exercise, many people with a RMD showed an increase of physical activity. However, it is hard to maintain a higher level of physical activity for years as part of daily routine [4-5].

Objectives: To identify and present tips, applications and illustrations that support people with an RMD to maintain their level of physical activity for a longer time.

Methods: Theoretical considerations and empirical findings guided the identification of tips. Care was taken that the tips and illustrations were translated into layman language and fitted in daily life of common people.

Results: Ten tips were found:

- 1) break the habit,
- 2) make sure you can do the exercise activity,
- 3) use aids if needed,
- 4) believe in a good outcome,
- 5) choose a physical activity that fulfils personal goals,
- 6) find a physical activity that you enjoy,
- 7) stop moving while it's still fun,
- 8) find a buddy,
- 9) make an action plan, and
- 10) find a nudge.

A "nudge" is a little push in the right direction that makes a person unconsciously perform physical activities. Examples are an outdoor photography hobby, a dog that comes to you with a dog leash in his mouth, or grandchildren that persuade you to go with them to the playground nearby. If a person with a RMD manages to find a nudge that stimulates instinctive moving without feeling the effort, then physical activity may be maintained. People differ a lot and must discover for themselves which tips help them to maintain physical activity. They must be aware that it may take up to two months for changed habits to stick.

Conclusion: The presented tips will help to maintain your level of physical activity. Nevertheless, be aware that effort and perseverance are needed to keep on moving. A challenge for the future is to get more knowledge of natural and pleasurable physical activities. Peers with successful experiences and