

Newsletter

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hpr News

Projet EULAR

Une enquête sur les besoins de formation des professionnels de la santé paramédicaux est en cours. Elle se déroule sous la supervision de Valentin Ritschl de l'Université de Vienne. L'enquête est disponible en 24 langues via le lien suivant. Vous trouverez des informations détaillées sur la première page : www.soscisurvey.de/HPR_edu_needs/

Nous encourageons tous nos membres à y participer – cela permettrait véritablement de faire progresser le projet. Dix minutes suffisent pour remplir le questionnaire. **Merci** d'y prendre part ainsi que de faire passer le mot au sein de vos réseaux personnels.

Symposium hpr 2021

Le symposium hpr aura lieu **jeudi 2 septembre 2021**. Il portera sur la thématique suivante: **«Arthrose: l'autogestion occupe la première place»**.

Vous trouverez le programme détaillé et le lien pour l'inscription sur notre site Web: <https://www.hpr-switzerland.ch/de/symposium>

Merci de transmettre le programme à vos collègues. Les inscriptions sont possibles jusqu'au 20 août.

Assemblée générale 2021

L'AG aura lieu le jeudi 23 septembre de **17h30 à 18h15** à **Berne**, au restaurant Casa d'Italia, Bühlstrasse 57, à deux pas de la Länggasse (voir aussi www.casaitalia.ch).

À l'issue de l'AG, le comité directeur vous invite à un repas au cours duquel vous pourrez échanger les un-e-s avec les autres. Les places peuvent être définitivement réservées par e-mail à v.ulli@bluewin.ch jusqu'au 10 septembre 2021 au plus tard.

Nous nous réjouissons de vous accueillir nombreuses et nombreux, que cela soit à Lausanne ou à Berne!

Contribution à la newsletter...

...de Sabine Gulden et Julia Hawich

Sidekick – l'équipe de coaching numérique pour les patient·e·s atteint·e·s de polyarthrite rhumatoïde

Outre le traitement médicamenteux, Pfizer souhaite également soutenir les patient·e·s dans leur vie quotidienne. Pfizer travaille pour cela avec SidekickHealth, une plateforme numérique gratuite. De manière ludique et avec des contenus utiles et interactifs, les patient·e·s atteint·e·s de maladies chroniques bénéficient d'un coaching numérique grâce auquel elles et ils peuvent apprendre à modifier positivement et durablement leurs habitudes en matière de nutrition, d'exercice physique ou grâce à la méditation « pleine conscience ». *

Pour en savoir plus: <https://sidekick.health/RA/HCPs>*

PP-INP-CHE-0272-JUN-2021

*Remarque: Pfizer n'a aucune influence sur le fonctionnement et le contenu de l'application SidekickHealth ou du programme qu'elle contient, mais soutient financièrement SidekickHealth dans le cadre d'une collaboration et met le programme qu'elle contient à la disposition exclusive des patient·e·s en Suisse.

Rétrospective du Congrès virtuel EULAR 2021

Agnes Kocher, présidente de hpr Switzerland, a présenté la Highlight Session hpr à la fin du programme hpr le 5 juin. Vous trouverez les diapos correspondantes ici : www.hpr-switzerland.ch/de/mitglieder/publikationen

Voici le texte de son allocution:

Dear audience

Thank you for inviting me to the EULAR congress and giving me the opportunity to talk about the highlights from the HPR program. (...)

Despite the online format of this congress, we had again a very broad offer of different sessions and poster presentations. And we had the opportunity to network and discuss in interprofessional EULAR debates and study groups.

During this session, I have the honor to pick out some of the most interesting presentations. And I must say this is a very personal selection. I would like to focus on self-management – Why does self-management matter? What is state of the art self-management support and how contextual factors influence this support? Furthermore, I would like to put the focus on eHealth which got enormous power during the pandemic.

I would like to start my highlights with today's last joint session. **Why self-management matters to patients and healthcare professionals?** Maria Andersson - a senior researcher from Sweden - gave us a very nice example on how a person's own feeling of being empowered can influence disease outcomes.

She presented the study results on **empowerment and its associations to disease activity and pain**. They used a longitudinal study design including patients from the time of their diagnosis and assessed them according to a structured protocol from diagnosis until 15 years later. Interestingly, the group of patients with low empowerment reported more tender joints, more pain and fatigue, and worse health-related quality of life and HAQ scores. The HAQ is an assessment of patients' capacity to perform activities of daily life. Furthermore, patients with high empowerment reported higher physical activity than people from the low empowerment group. They can conclude that in RA, low empowerment is associated with worse overall health and interventions aimed to improve empowerment may also improve mastering pain, physical function, and physical activity.

But it's not just pain, fatigue and physical function that needs to be mastered by people with arthritis.

Professor Bente Appel from Denmark showed us a very nice slide illustrating the **many challenges people with arthritis may face during their disease course**. Because people with a chronic disease live more than 99% of their time outside the healthcare system, the ability to self-manage is an essential component of care. What people do in that time affects their health, quality of life, and utilization of healthcare resources.

What I recognize in clinical practice since years is that many healthcare professionals including rheumatologists are not aware of what self-management support exactly is. For many of them, self-management support involves a mix of information and education.

Self-management support has been identified as the **most challenging part of chronic care**. Professor Appel provided a definition that makes clear, that it goes beyond traditional patient education: It includes processes supporting **problem-solving skills, self-efficacy, and transfer of knowledge into real-life situations**. For self-management interventions, educational, behavioral, and cognitive approaches should be used.

I would now like to present a few project examples that showcase how self-management and clinical outcomes can be improved using these principles.

A first study I would like to highlight is focusing at the patient-practitioner encounter. For their systematic review and meta-analysis, Ayah Ismail and her research group from Nottingham aimed to identify modifiable contextual factors that can improve clinical outcomes in any disease population. They found 15 RCTs that met the inclusion criteria. Their main finding was that **patient active involvement and practitioner positive communication skills** have a positive significant effect on outcomes, specifically on patient experience outcomes. Optimizing these modifiable factors in clinical care can improve patient-centred outcomes. Unfortunately, details on the interventions used was often lacking in the studied RCTs. Therefore, I would like to bring your attention on personalized goal setting, which is an important cornerstone of chronic illness management.

Dr. Erika Mosor from Vienna explained in her talk why **personalized goals are important** and how they can be assessed. Reaching disease remission does not necessarily mean that the well-being of a patient is at a sufficient level. Therefore, individualized goals should be taken into account as an important outcome measure because the definition of goals can improve patient-provider communication and coordination, and support behavior change. At the end, achieved goals can motivate all people involved by giving them a timely feedback. But individualized goals are often not captured within existing tools. Dr. Mosor presented several tools of which I would like to highlight only one:

The goal attainment scale intends to measure self-defined goals using a 5-point scale ranging from minus 2 to plus 2. And the expected level of goal attainment is set at 0. So the described circumstances of minus 1 and minus 2 would be below the expected level. On the right side you can see an example provided by Dr. Mosor which showcases the wording of such goals. Such goals are more verifiable than for example "I want to cope better in my everyday life". My opinion is that health professionals should brief patients that they are able to draw attention on the importance of such personalized goals when communicating with their physician or therapists.

Because with the COVID-19 pandemic, web-based self-management support became more and more used and accepted. Therefore, I would like to highlight the web-based, peer-supported exercise program for people with hip or knee osteoarthritis that was evaluated by Kenth Joseph from Norway.

The researchers delivered a 12-week intervention through a web-based platform from the patient association of Norway. It included weekly exercise programs, weekly motivational messages, a website with information on OA and exercise, and assigned peer-supporters.

Dr. Joseph and colleagues found that 7 out of 10 patients were willing to participate in the program, and 6 out of 10 provided follow-up data. The website was rated "acceptable" and exercise level and understandability of the program was found to be just right for most of the patients. But the peers were not contacted, which raised some questions. At the moment, the reason for the non-use of peers is not known.

The next highlight I have for you, is a study on **remote management of RA vs. routine follow-up care** presented by Dr Mwidimi Ndosu from UK – who is also the Chair-Elect of the EULAR health professionals. Dr Ndosu and his colleagues aimed to determine the agreement between remote treatment decisions and decisions based on routine outpatient monitoring appointments. They included RA patients starting a new biologic therapy. The same patients that were assessed by a doctor in the outpatient clinic were also completing monthly self-assessment questionnaires at home. Only the results of these self-assessments were available for the independent health professionals to make virtual decisions.

Overall, they analyzed 57 matched decisions. 7 clinicians made outpatient changes to the biologics, but only 1 was made by the independent health professional. The results showed a fair agreement between decisions made by outpatient clinicians and decisions made virtually by health professionals. The authors conclude that remote monitoring using patient self-assessment was feasible. And patient reported outcomes can give patients confidence that they are looked after, even if they are not in the clinic. But further work is needed to know if adding blood test monitoring could improve remote management. And people that are not able to fill-in such self-assessments also should receive appropriate care.

The last highlight I have for you is a study presented by Bas Hilberdink – a physiotherapist and health psychologist from the Netherlands. He presented the results of a **pilot implementation of enhancements in supervised group exercise for people with axial spondyloarthritis**.

With regard to the recent evidence, they implemented

- high-intensity aerobic exercise including intensity monitoring
- personalized assessments and
- patient education using an app.

The implementation strategy included a one-day training for the training supervisors and a one year telephone support for the supervisors.

The aim of the study was to evaluate the effect and feasibility of implementing these enhancements.

To evaluate the implementation effects of this one year intervention, they used several assessment. A survey was sent to 95 group exercise participants. In addition, they conducted interviews with four group supervisors.

The survey was returned by 60 participants. What they found was that 33% experienced improved functioning. But there was no significant effect in health status and exercise frequency. There was a significant improvement in the aerobic capacity measured with the 6-minutes walk-test and 37% improved functioning according to the API-test.

In the feasibility evaluation, they found that the enhancements were only partially implemented.

- Patients were satisfied with the high intensity aerobic exercises and also with the personalized assessments.
- But patient education lacked implementation. Only 21% were familiar with the axSpA exercise app and only 2% used the app.

The research group concludes that for a nation-wide implementation a more extensive strategy addressing specific barriers is needed.

To conclude, I think, these highlights presented here nicely showcase how important it is that providers and patients are working together. I know that health care is even more complex than building a house – However, both require joined forces and diverse expertise to **achieve high quality and sustainable results**. In this regard, my opinion is that the expertise of patients and professionals are equal important for example when it comes to the definition of treatment goals and outcomes. What strategies do you think are important to build this house together? Perhaps we can further discuss this at the end of this session.

So, I would like to close my presentation and would like to thank you for your attention.

(...) I very much hope that we will be able to enjoy excellent presentations and coffees at the next year's congress in Copenhagen in real world.

Announce préliminaire Congrès EULAR 2022

Le prochain congrès EULAR se tiendra du **1.6. au 4.6.2022** à Copenhague au Danemark.

Contributions à la newsletter hpr

Les contributions pour la prochaine newsletter sont les bienvenues. Nous encourageons vivement toute personne désireuse d'écrire un article d'actualité intéressant à nous le faire parvenir.

Pour cela, veuillez contacter Brigitte Freyhof (brigitte.freyhof@usz.ch).