HPR core competence recommendations

Thea Vliet Vlieland, co-convenor of the EULAR Recommendations for the generic core competences of health professionals in rheumatology task force, brings an update on the newly-published recommendations

EULAR has undertaken a considerable number of educational activities for health professionals in rheumatology (HPR) over recent years – such as the EULAR HPR online course and bursaries for educational visits. In order to expand activities and develop a core educational curriculum for HPRs, it was necessary to formulate underlying competences. Sets of generic core competences had been developed at the national level in a few countries but they were lacking an international perspective.

Significant variation

Therefore, in 2017, EULAR convened a task force aimed at developing recommendations for the core competences of HPRs. The number of different professions among HPR is, however, large, and there is significant variation between – and among – countries regarding their tasks and responsibilities. As a result, the complexity of the project was scaled back to focus on the core competences that nurses, physical therapists (PTs) and occupational therapists (OTs) have in common.

Task force members – including rheumatologists, nurses, PTs, OTs, patient representatives, an educationalist, methodologists and researchers from 12 countries – followed the updated EULAR Standard Operating Procedures. During the first task force meeting, members established definitions and discussed clinically relevant questions regarding HPRs’ education, skills and practice. They then developed research questions by consensus to form the basis of a systematic literature review.

Medical and educational electronic databases were systematically searched to identify and evaluate studies about the competences, roles, knowledge, attitudes, skills and educational needs that different HPR professional backgrounds have in common. Studies specific to nurses, PTs or OTs were used to confirm the findings. In addition, the task force contacted national HPR organisations to supplement its findings.

Considerable efforts

The systematic literature review yielded 79 full-text papers, 20 of which specifically addressed the generic competences, knowledge, skills, attitudes or educational needs that HPRs have in common. Most of the studies had a qualitative design, resulting in considerable efforts by the task force to assign an appropriate level of evidence to the materials.

During the second task force meeting, task force members presented and discussed the findings of their literature review, and developed the wording of the overarching principles and recommendations. If at least 75% of the task force voted to approve a principle or recommendation, it was accepted. If not, further discussion, revisions and voting could follow. The task force’s average level of agreement for each recommendation on a 0-10 scale ranged from 9.42 to 9.79.

>> Continued on page 2
In total, the task force developed three overarching principles and 10 recommendations for the generic core competences of HPRs. The principles and recommendations emphasise the need for health professionals to communicate effectively, provide person-centred care, and be knowledgeable about the aetiology, pathophysiology, epidemiology, clinical features and diagnosis of common rheumatic and musculoskeletal diseases (RMDs) and their impact on all aspects of life (see boxes).

**International consensus**

A next step will be to get feedback on the recommendations from a wide range of countries and different HPR disciplines. In addition, one action to be taken is to review the content of current EULAR educational activities to check whether all competences are covered.

Tanja Stamm, Vice President of EULAR representing HPRs said: “This has been a huge undertaking for the task force. Given the variations, I am grateful for their diligence in achieving an international consensus on the core competences.”

**The three overarching principles**

- Effective communication skills and a biopsychosocial approach in the assessment, treatment and care of people with RMDs are of paramount importance for HPRs.
- Person-centred care and patient advocacy are fundamental in the care delivered by HPRs for people with RMDs.
- An evidence-based approach, ethical conduct and reflective practice are essential for HPRs.

**The 10 recommendations**

1. HPRs should have knowledge of the aetiology, pathophysiology, epidemiology, clinical features and diagnostic procedures of common RMDs, including their impact on all aspects of life.

2. Using a structured assessment, HPRs should identify aspects that may influence individuals with RMDs and their families, including clinical characteristics, risks, red flags and comorbidities; limits to their activity and participation; and personal and environmental factors.

3. HPRs should communicate effectively to make contributions to other healthcare providers and stakeholders in RMD care and to collaborate with other healthcare providers, and signpost or refer where appropriate to optimise the interdisciplinary care of people with RMDs.

4. HPRs should have an understanding of common pharmacological and surgical therapies in RMDs, including their anticipated benefits, side effects and risks, and use this knowledge to advise or refer as appropriate.

5. HPRs should provide advice on non-pharmacological interventions, treat or refer as appropriate, based on the evidence, expected benefits, limitations and risks for people with RMDs.

6. HPRs should assess the educational needs of people with RMDs and their carers to provide tailored education using appropriate modes of delivery, relevant resources, and evaluate their effectiveness.

7. HPRs should take responsibility for their continuous learning and ongoing professional development to remain up-to-date with the clinical guidelines and/or recommendations on the management of RMDs.

8. HPRs should support people with RMDs in goal setting and shared decision making about their care (e.g. identify, prioritise and address their needs and preferences, and explain in lay terms).

9. HPRs should support people with RMDs in self-management of their condition. This encompasses selecting and applying the appropriate behavioural approaches and techniques to optimise their health and well-being (e.g. engagement in physical activity and pain and fatigue management).

10. HPRs should be able to select and apply outcome measures for people with RMDs, as appropriate, to evaluate the effectiveness of their interventions.

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**Do you have good news for the newsletter?**

Ever since 2000, the HPR newsletter has provided the main information channel of health professionals in rheumatology within Europe. The newsletter is published twice a year, featuring the work of health professionals and all aspects of multidisciplinary collaboration. Please share tips about health professionals theses, projects and new research themes in the musculoskeletal field. Prescribe the newsletter free of charge to colleagues at www.eular.org/health_professionals.cfm.

Please contact Kate Betteridge at kate@katebetteridge.me.uk if you have ideas for future articles.
Bringing EULAR Recommendations to life

By Els van den Ende, Implementing Best Practice for Hand Osteoarthritis project leader

Patient information, education, hand exercises and information on joint health are core elements of the 2018 EULAR Recommendations for the Management of Hand Osteoarthritis (OA). However, information about the specific type of exercises and the specific content of patient education is not provided in the recommendations.

Hand exercises: bringing EULAR Recommendations to life

Filming was successful and inspiring

“Initially, we planned to produce three short videos, but the number increased because the filming day was so successful and inspiring,” said project member Melanie Holden. “Patient representative Christine demonstrated her large collection of kitchen and garden aids – enough material for two separate films – with great professionalism.”

The films will be subtitled

Other topics covered include information about hand OA, and explaining and demonstrating splints and exercises for hand OA. Draft versions of the videos were broadcast during the EULAR Congress and the feedback we received from HPRs and patients helped us to finalise the films. The result is six different films.

These films will be part of the EULAR online course for health professionals in rheumatology. With EULAR’s help, we will look for ways to make them available on a broader platform for both patients and health professionals. In the coming months the videos will be subtitled in French, Italian and Spanish.

The following people contributed to the videos: Kate Betteridge, Laura Campbell, Krysia Dziedzic, Els van den Ende, Nicola Evans, Martine Frich, Carol Graham, Elsie Greibrokk, Melanie Holden, Victoria Jansen, Ingvild Kjeken, Margreet Kloppenburg, Helen Myers and Christine Walker.

The films are freely accessible through EULAR’s School of Rheumatology. We hope they will prove useful in clinical practice.

Empowered2work – supporting people with RMDs

By Erika Mosor, pilot project group leader

Up to 15 people with rheumatic and musculoskeletal diseases (RMDs) will be trained to become trainers to support other people with RMDs in their countries to stay in – or return to – paid or voluntary work, or education as a result of a EULAR health professional in rheumatology (HPR) pilot project. During a workshop in Vienna from 22-23 January 2020, “Empowered2work” will provide trainees with basic knowledge and educational materials regarding health promotion in the workplace, such as activity pacing, exercises, ergonomic principles etc.

“Experts in their own health”

The workshop plans to address topics such as handling heavy objects, adapting a computer workstation, keeping moving (exercises at work), taking a deep breath (rest, activity pacing, occupational balance) and communication skills. To better include the requirements and needs of participants, and to get input on the planned topics and other topics that might be important from their point of view, we will conduct a short survey among the workshop patient participants in autumn 2019.

“In this pilot project, we would like to empower people with RMDs to be engaged in work and enjoy long and productive careers in a variety of occupations as long as they need to and want to,” said Tanja Stamm Vice President of EULAR representing HPRs. “The underlying concept is to view people with RMDs as experts in their own health at work and in supporting others in similar situations.”

In the future, those patients who complete the workshop to become trainers will pass on their knowledge and experience to other people in their workplaces, and at conferences and meetings of international and national patients organisations. We hope the outcomes of the project will also support EULAR’s Don’t Delay, Connect Today “Time2work” campaign activities.

Members of the project team

Birgit Barten, Annelies Boonen, Carina Boström, Boryana Boteva, Razvan Dragoi, Ricardo Ferreira, Erika Mosor (project leader), Souzi Makri, Romualdo Ramos, Andreas Sönничsen and Tanja Stamm.
Assessing implementation of the EULAR Recommendations for patient education

By Mwidimi Ndosi and Heidi Zangi, EULAR Study Group on Patient Education leaders

Patient education (PE) is integral to the management of inflammatory arthritis. However, great variations exist across Europe in the content and in how patient education is delivered. In 2015, EULAR developed evidence-based recommendations for PE to address these variations and improve the quality of PE for people with inflammatory arthritis across Europe.

Having the recommendations is very good, but it would be naïve to expect these to automatically translate into improved patient care and desired patient outcomes. To avoid the evidence-practice gap, focused efforts are required to disseminate the recommendations to all stakeholders such as clinicians, health professionals in rheumatology (HPRs), patients, professional organisations and patient groups.

Assessing acceptability and applicability

The EULAR Study Group on Patient Education (STOPE) created an online survey to assess acceptability and applicability of the recommendations to practitioners. This was translated into 18 languages and disseminated to rheumatologists, nurses, physiotherapists, occupational therapists, podiatrists and other HPRs. Patients have also been consulted to assess their acceptance of the recommendations. With the help of country champions and patient research partners, the survey has been disseminated in 24 countries and in 18 different languages in Europe, India, Hong Kong and Japan (see above maps).

From the survey, we hope to see the indicators of implementation such as acceptability, adoption and appropriateness of the recommendations in different clinical contexts. Given the variation in healthcare systems, it is important to examine what works, for whom and under what circumstances – and how the recommendations will be adapted in ways that are accessible and equitable. This will help inform further promotion and how well the recommendations can be applied in practice and, therefore, translate into patient benefit.

Sarah Bennett, research associate working on the project, said: “This project has enabled HPRs to be aware of the recommendations and to think about how each one of them could be adopted into practice. For people with inflammatory arthritis, this project may have given them an idea of what to expect from their rheumatology consultation with their HPR.”

From the Chair

From Rikke Helene Moe, Chair of the EULAR Standing Committee of Health Professionals in Rheumatology

What a successful congress we had in June. I would like to thank all the participants, speakers, abstract presenters, reviewers, chairs and our programme committee who volunteer, sharing their knowledge, skills, enthusiasm and time to make this prominent event happen.

A few years back we discussed options to strengthen our scientific networking platform across professions. One of the most fruitful changes has been moving from profession-specific to topic-specific EULAR Study Groups (SGs). This has opened up a new platform for enthusiastic people to discuss and collaborate on taking important initiatives further.

“You need good treatment if you are ill”

Because it can be difficult to find the right submission category, the Standing Committee has also discussed congress abstract topics. The deadline for abstract submissions for the 2020 congress in Frankfurt is the end of January. I would urge all health professionals in rheumatology (HPRs) to submit your work under the new category “interdisciplinary research”. How you “label” your abstract when submitting has consequences for congress topics and the context where the abstract may be presented or displayed. Importantly, it affects eligibility for bursaries, prizes etc.

No matter where you are from, you need good treatment if you are ill. And, within the field of rheumatic and musculoskeletal diseases, good, up-to-date information about high quality interdisciplinary treatment is now more accessible than ever thanks to the HPR classroom in the EULAR School of Rheumatology. Anyone can sign in.

“We are focusing on overcoming these barriers”

Communicating across borders, languages and cultures is challenging so we are now focusing more on how to overcome these barriers through initiatives like the school and a communications strategy.

Tanja Stamm and I are very happy with the HPR leadership team: we are honoured to welcome Thea Vliet Vlieland as Vice President Elect, Ricardo Ferreira as Chair Elect and Mwidimi Ndosi as the co-opted member. And as Annette de Thurah and Yeliz Prior leave the team, we want to thank them for their dedication.

Rikke Helene Moe

Sarah Bennett
Be active: Expand your knowledge and our network

From Tanja Stamm, EULAR Vice President representing Health Professionals in Rheumatology

Interaction and networking are essential for achieving excellence in clinical practice and research for health professionals in rheumatology (HPRs). Two examples of these activities are the new interactive congress sessions, and the interaction and networking which takes place in the EULAR HPR Study Groups.

At this year’s EULAR Congress in Madrid in June, new interactive session formats were tested and found to be a great success. An example was the Friday afternoon session. In this session, an excellent presentation by Prof. Josef Smolen describing the importance of research for HPRs was followed by a discussion on HPR research. Dr. Mwidimi Ndosi and Dr. Romualdo Ramos led the interactive part of the session which included a debate between the perspective of quantitative and qualitative research. In addition, the audience raised several important issues for debate and future development. One example is that EULAR should not exclude and separate HPR abstracts from the scientific topics.

Furthermore, it was suggested that HPRs should have thematic leadership in areas in which HPRs are excellent. These areas are mainly generic and include physical activity, patient education, functioning and activities, fatigue, pain, work, outcomes research, adherence among others. These generic topics are also in line with the overarching topic-focused study groups that EULAR has introduced in place of the (mainly) profession-specific ones.

EULAR has endorsed the following groups within the sphere of health professionals:

- **EULAR Non-pharmacological Treatment of Autoimmune Connective Tissue Diseases Study Group**: The study group aims to improve and standardise care and, thereby, reduce variation in care of patients with CTDs within the EULAR member countries.
- **EULAR Work Rehabilitation in People with RMDs Study Group**: The study group aims to bring together a multi-disciplinary team of expert health professionals, researchers, academics and patient partners with RMDs to encourage a cross-cultural and inter-disciplinary approach to support people with RMDs who are struggling to remain in work and/or return to work due to the impact of RMDs on their work participation.
- **EULAR Nurse Research and Strategy Group (REST)**: The EULAR nursing task force has composed a research agenda and an educational agenda that increasingly leads to European and global initiatives from rheumatology nurses. It aims to promote excellence in research by nurses, education for nurses and collaboration of nurses.
- **EULAR Physical Activity and Exercise Therapy Study Group**: There is convincing evidence that physical activity and individualised exercise improve symptoms and functioning, cardiovascular health and even disease activity. Yet these non-pharmacological treatment strategies are poorly implemented. This study group is focused on all aspects of making physical activity and exercise happen.
- **EULAR Foot and Ankle Study Group**: The purpose of this group is to encourage wider communication within the EULAR family for HPRs with an interest in foot and ankle care, and to encourage greater participation during the annual EULAR Congress.
- **EULAR Patient Education Study Group (STOPE)**: The overarching aims of STOPE are to (i) promote excellence in patient education research, (ii) disseminate research evidence, (iii) support implementation of EULAR recommendations that have a patient education approach and (iv) promote collaboration among professionals and patients interested in patient education across Europe.

“I can’t encourage you enough to get involved”

I can’t encourage you enough to get involved in the study groups. They are stimulating, educational and a fantastic means of growing your networks. In addition, their excellent work helps raise the profile of health professionals in rheumatology and highlight our outstanding work. The more our network grows and the more active it is, the better it will perform. All active and engaged HPRs contribute to excellence in clinical practice and research and grow the EULAR HPR family.

To get actively involved, please contact the study group leaders.

“Networking within a study group is of great importance”

To interact and network within a study group is of great importance – not only for experienced clinicians and researchers to share their knowledge, but especially for clinicians and researchers who are “young” in their careers. EULAR Study Groups are established networks in their respective fields and play an active part in the research and treatment of rheumatic and musculoskeletal diseases (RMDs).
The EULAR Annual European Congress of Rheumatology gives health professionals in rheumatology the opportunity to come together for a range of meetings, sessions and activities. Bente Appel Esbensen and Nina Brodin both gave official highlight presentations at the end of the congress. They share with you their own memorable moments from an active and engaging congress in a hot Madrid last June.

What were your programme highlights from the 2019 congress? Did you identify any common themes?

Bente Appel Esbensen, Research Manager, Associate Professor, Centre for Rheumatology and Spine Diseases, Denmark: I want to emphasise the sessions “Rehabilitation: Opening Pandora’s box”, “Exercise – more than a wonder drug”, “How not to smoke like a chimney?” and “Teenage look in the mirror (sexuality and body image meeting health care)”. The common themes were physical activity, lifestyle issues, what does and what does not work, patients’ responsibility for their own health and also the health professional in rheumatology (HPR) role in patient self-management.

Nina Brodin, Associate Professor, Senior Lecturer, Karolinska Institutet division of physiotherapy, Sweden: It wasn’t easy to choose what to present as the highlights from the 63 oral presentations and the 148 posters. Many contributions were thought-provoking and of high quality. The congress started with a series of really interesting presentations, setting the scene for this congress and for the topic of rehabilitation and HPRs. Prof. Ann Bremander stressed the importance of bridging the gap between healthcare sectors. She talked about the challenge of providing evidence of an effective and high-quality rehabilitation service, and the advancements and challenges in providing person-centred care.

This was followed by Prof. Thea Vliet Vlieland who talked about how care also needs to be personalised – tailored to a person’s individual situation, abilities and needs. We need a holistic approach to reach this, and the biopsychosocial model and the International Classification of Functioning were suggested as frameworks to move closer to this goal. My highlights after that opening included the two award-winning abstracts: “Targets for reducing premature mortality in older adults with osteoarthritis: results from a novel path analysis within a cox proportional hazards model” from Ross Wilkie and colleagues, and “Does occupational therapy delay or reduce the proportion of patients who receive thumb carpometacarpal surgery? A randomised controlled trial” by Else Marit Gravås and colleagues. Both were of high scientific quality and novel in their areas, respectively.

In addition, what caught my interest were “Barriers and facilitators to requesting and receiving psychological support for people with rheumatoid arthritis and adults with juvenile idiopathic arthritis” presented by Hayley McBain, and “Short-term effect of occupational therapy intervention on hand function and pain in patients with thumb base osteoarthritis – secondary analyses of a randomised controlled trial” presented by Ingvild Kjeken.

What are the pros and cons of putting together the Highlights Session of the HPR programme during the congress?

Bente: To me, the pros are the possibilities for the audience to reflect on the intense days at the EULAR Congress, to stop and ask: “What would be of interest to bring back to my clinical practice” and “In which ways might this improve conditions for my patients?”.

It is rather stressful to be the person who will give the highlight presentation as the last presentation at the congress. You need to be very attentive and focused on the specific task in order to give a short, accurate and rewarding presentation, binding things together, in relatively few minutes. After all, it is important that the congress participants get a good presentation as this is the very last presentation of the event.

Nina: It sometimes feels stressful to manage to attend all the HPR sessions (and to have energy left at the end of the day) but, at the same time, it is good to keep focused and not run between different buildings and totally different research subjects. This year however, I would have loved to attend some interesting joint HPR/scientific sessions scheduled simultaneously with the HPR sessions. But, thanks to the recording of sessions, I can listen to them afterwards.

You must have heard a lot of new research being presented during the congress. What has really excited you?

Nina: I very much appreciated the presentation by Hayley McBain on the need for psychological support for people with rheumatoid arthritis (RA) and adults with juvenile idiopathic arthritis (JIA). Maybe the word “exited” isn’t the best, but it was an eye-opener to an area that is not at all described or discussed to the extent it probably should be.

Bente: I am convinced that the opening presentation from our past president Annette de Thurah “HPR news over the last year(s)” gave an excellent overview of who we are, how the development within EULAR HPRs has evolved, how we are linked together with the other two pillars (medical doctors and people with RMDs), what is the strategy for the future and how can we possibly reach the goals to improve treatment and care for people with RMDs.
What was your personal or professional stand out moment of the congress?

Nina: I really enjoyed the session “Exercise – more than a wonder drug”. I may be a bit biased though because it is my research area. I really enjoyed the way in which the presenters guided us from physiology to behaviour – all related to physical activity. The presentations were stuffed full of both technical and practical content. For me, this was really something to take home and start using immediately.

Bente: During the session “Teenage look in the mirror”, Prof. Jelena Vojinovic from Serbia managed to touch the entire audience with her presentation. She read, among other things, correspondence between her and Petra, a teenager with Wegener granulomatosis, where we all gained insight into how painful it can be to be a teenager with an RMD. We learned how this teenager – through time, through the support of other people and, not least, through her own strength and strong will – found a way to reconcile with her destiny and feel beautiful in life despite visible signs of her disease.

You are both members of a EULAR Study Group. What benefits did you get from attending the face to face meeting?

Bente: I want to mention the opportunity the study groups present us with to meet European colleagues, and discuss issues around clinical practice and research questions. I appreciate the chance to build networks across countries and to get new ideas for improving patient care. For instance, this year I got to know a colleague from a country I do not usually work with. We have now described a project and are applying for funding together. Such things are so inspiring.

Nina: Unfortunately, I didn’t have time to attend this year’s study group meeting as I was scheduled at another meeting at the same time – which I hope you will see the fruit of at future EULAR Congresses.

You have both attended the annual congress for a number of years now. How do you feel it has improved over the years and what makes you want to come back every year?

Bente: In a way, I think EULAR is getting better and better year on year. Perhaps it also has to do with my network getting bigger and bigger. My interest in rheumatology is constantly enhanced and I am, basically, curious to learn new and more things. EULAR offers that. That is also why I will be going to Frankfurt next year for the EULAR Congress. I am already looking forward.

Nina: My feeling is that the overall quality increases with every congress. Even though the focus area might not be “for me” every year, I always come home filled with either new research ideas, new contacts or with thoughts about how to improve my clinical practice in the dialogue with patients. Sometimes with all three… as well as a new pair of shoes.
Driving innovation and excellence

Study groups give professionals and patients working in rheumatology a chance to play an active part in the research and treatment of rheumatic and musculoskeletal diseases. Annette de Thurah, former Chair of the Standing Committee of Health Professionals in Rheumatology, introduces the EULAR HPR Study Groups, sharing insight into their value and how to get the best from them.

EULAR Study Groups offer health professionals in rheumatology (HPRs) an exciting opportunity to expand their networks, develop research, extend good practice across the EULAR countries, and drive innovation and excellence in their chosen field. If you are not involved, you should be!

The purpose of a EULAR Study Group (SG) is to give people a platform on which they can meet and discuss shared fields of study. EULAR study groups are focus groups within the five areas of Clinical Affairs, Epidemiology and Health Services, Health Professionals, Investigative Rheumatology and PARE (People with Arthritis and Rheumatism). Each study group is connected to a EULAR Standing Committee, which supports it. Each standing committee can apply for EULAR endorsement of a study group, and can also apply for a title for a EULAR Study Group.

Conditions for establishing a study group

Although anybody can apply for a new study group through their standing committee, all new study groups must be approved by the Executive Committee of EULAR. The conditions for setting up a study group are that there must be:

- a specific topic
- a well-defined group leader
- representation from at least three European countries,
- no less than 10 members
- be open to any new applicant
- include patients.

EULAR endorses each study group and hosts the yearly face-to-face meetings during the annual congress by offering meeting facilities, but it does not support the projects or products of the study group.

A multidisciplinary approach

Previously, most of the SGs within the HPR field were profession-specific groups. However, viewed in the light the multidisciplinary approach we have for the treatment and care of people with rheumatic and musculoskeletal diseases (RMDs), the HPR Chair actively worked to transform the profession-specific SGs into groups that are more topic specific. With this approach, we can now also invite members from all three EULAR pillars into the study groups and be open to broad-based co-operation.

By taking the strategic lead over these HPR study groups, the HPR chair is able to indicate areas where we have a strong position within EULAR, and help raise awareness of important topics where HPR are the experts.

Today, the following HPR study groups exist:

- STOPE – patient education
- Non-pharmacological Connective Tissue Disease
- Work Rehabilitation in People with RMDs
- Foot and Ankle
- Physical Activity & Exercise
- Nurses Research & Strategy (REST)

Sign up, sign up

The HPR EULAR Study Groups are open to everyone who has an interest in a specific topic, and the HPR Standing Committee is really keen to encourage HPRs to sign up to a group and become active in its field of research. To become a member of a group, simply contact the SG leader either by email (see page 19) or by showing up at the annual face-to-face meeting which is held during the EULAR Congress.

Membership of a study group offers many advantages. It can be a platform for:

- gaining new information within a specific area
- providing the opportunity to share ideas and learn from others
- starting new projects within EULAR
- writing up proposals for congress sessions
- extending your international network and getting to know people from all over Europe who share your interest in a specific topic.
Helping you become more visible

Finally, HPR members of task forces within other standing committees are sometimes chosen from the HPR study groups. So, being an active member of an HPR study group can also help you to become more visible in the large EULAR family.

The HPR EULAR Study Groups play a decisive role in supporting EULAR within the specific areas where HPRs are the experts. They can point to new areas of research which can, ultimately, improve the treatment and care available to people with RMDs.

If I haven’t convinced you to sign up yet, then read about the experiences of three people who appreciate the value of being actively involved.

A sense of community for small professional groups

By Dr. Simon Otter, a podiatrist from the UK and member of the EULAR Foot and Ankle Study Group

I have been fortunate to attend the EULAR Annual Congress of Rheumatology on several occasions during the past decade. Notably, there has been an increase in both the amount and quality of research devoted to foot and ankle complaints. Colleagues are to be congratulated as this remains an area of considerable concern to those living with rheumatological disease.

A tremendous step forward

The advent of a foot and ankle SG represented a tremendous step forward in terms of broader recognition, in becoming formalised under the EULAR umbrella and the opportunity to widen professional networks. The group also presented a much needed opportunity to co-ordinate pan-European work and the opportunity to apply for different funding streams to further support research.

The group has regular online meetings throughout the year, in addition to an annual face-to-face meeting within the wider EULAR conference programme. HPRs with an interest in foot and ankle disease have the opportunity to learn from one another, identify and share areas of good practice in addition to the sense of community the SG provides – something which is often lost when practitioners are part of small professional groups which are sometimes working in isolation.

Resource for individuals in different countries

The group is relatively young, and still has a modest number of members, but it has already completed one Europe-wide survey with further research in the pipeline. We hope this baseline data will serve as a resource for individuals in different countries to develop their clinical services further to benefit patients. Without this type of information, it is difficult to justify the need to improve care to commissioners and budget holders.

Going forward, our aims would be to continue to strengthen the core membership and seek to be successful with funding bids to continue this important work.

From the scientific perspective

By Prof. Loreto Carmona, a rheumatologist from Spain and member of the EULAR Congress Scientific Committee

EULAR Study Groups are needed to focus on specific problems or challenges and to really achieve goals. We can get very creative during interactions at congresses or meetings, and great research questions can arise, but things actually need to be done. Study groups are meant to move these inspirational moments forward. A truly great study group will get its hands dirty and initiate studies, courses, events or taskforces.

Value to EULAR and the field of rheumatology

Study groups are bottom-up initiatives that appear and develop because the field is boiling at a specific point. They strengthen connections between high level researchers, clinicians and even patients. They present a card to choose from when designing the congress programme and thinking about hot topics. They also define courses and prioritise recommendations.

Focus always makes objectives clearer and, when objectives are clearer, the destination is also clearer. That is the reason why topic based study groups reach their goals faster. Broad study groups, similar almost to actual EULAR Standing Committees (StC), need more time to achieve their goals and sometimes overlap with the tasks of the StC.

EULAR is an outstanding influencer because it has forced the interaction between the three pillars of scientists, health professionals in rheumatology and patients. Imagine working hand-in-hand with a common goal in a topic? The strength and the focus would move mountains!

What the HPR perspective brings

The HPR perspective is sometimes disregarded by clinicians as being of lower quality. We often ask HPRs foolish questions instead of using them as true partners. HPRs are stronger by far in many aspects than clinicians – qualitative research for instance. If you want to implement anything, you need good qualitative research on which to base the strategy and I know fewer clinicians with these research skills. Further, the HPR perspective is much closer to the patient and they can help in designing better questions in our studies. I have always enjoyed the level of science in HPR congress programmes. Why would anyone think that an HPR brings no value to a study group? Nonsense. They are as good as researchers or better than most clinicians.

I learn something from hearing the HPR viewpoint every day. I follow many HPRs on social media and enjoy their viewpoints, the practicality of their research ideas and how much they enjoy their professions. I must confess that I cannot say
that I am not an HPR myself: I had one year of psychology at college and taught for two years at a physical therapy school. Despite the fact that I am a rheumatologist, I work with patients, not on patients. Just like health professionals in rheumatology.

Establishing a new study group

By Carina Bostrom, a physiotherapist from Sweden and leader of the newly-created EULAR Non-pharmacological treatment of autoimmune connective tissue diseases Study Group

In 2011, the European Health Professionals network in systemic sclerosis (EUSHNet) was formed by health professionals in rheumatology (HPRs) working with patients with systemic sclerosis (SSc). The EUSHNet, led by Prof. Anthony Redmond and Dr. Els van den Ende (and in which I also was involved), published a systematic review showing that the body of knowledge regarding non-pharmacological care in SSc is limited. This was due to the wide variability in interventions and outcomes in the relatively uncommon, but highly disabling disease. A second study showed that non-pharmacological care in SSc was varied in Europe with respect to the reasons for referral, treatment targets and the content of interventions.

Widening the scope

Different HPRs came together during EULAR Congresses over the last few years and expressed a wish for a wider network group regarding treatment of patients with other connective tissue diseases (CTDs) where there are common features and treatment approaches facing clinicians and patients. Many of these diseases are rare and complex, and clinical practice guidelines are missing. However, there is some evidence for positive effects from non-pharmacological interventions in these diseases.

It was thought that a EULAR Study Group focusing on the areas of commonality across CTDs would facilitate research activities and help direct consensus. An opportunity for starting such a group was expressed by the EULAR HPR Standing Committee in autumn 2018. I then started to write an application for a new SG, and the support that the founding members and I got from the standing committee was of great importance and contributed to the approval of the application.

The overarching aim of the SG is to improve and standardise care and, thereby, reduce the variation in care of patients with CTDs within the EULAR member countries. To achieve this, the group has several objectives of which some are mentioned here:

- identify areas where variation in care and rehabilitation exists
- develop evidence-based guidelines for the care of people with CTDs through systematic reviews and EULAR Recommendations for non-pharmacological treatment
- implement better evidence and standardised care in pathways across EULAR member countries.

Expert multidisciplinary group

It is fundamental to understand and follow the needs of people living with CTDs. Therefore, people living with CTDs are important collaborators. Bringing a multidisciplinary group of expertise in CTDs together, from a range of EULAR member countries, will help significantly in building a critical mass to work systematically on evidence-based outcomes, treatments, recommendations and implementation of non-pharmacological treatment of these diseases.

As we are a newly-approved study group we do not have any results yet. However, in order to increase the knowledge about CTDs and non-pharmacological treatment, some of the founding members have started to write a module on SSc for the EULAR HPR School of Rheumatology. We have also decided that we will apply for a task force for EULAR recommendations of non-pharmacological treatment in CTDs.

We had our first meeting at the EULAR Congress in Madrid in 2019 and we have kept in contact via email. This works very well at the moment because the group is not that big. A network group within LinkedIn will be created during the course of autumn 2019. The SG members and I are looking forward to contributing with increased knowledge about non-pharmacological treatment in CTDs and implementing the results from our activities.

We offer a warm welcome to new members of the study group and to the next meeting at the EULAR Congress in Frankfurt in 2020.
The importance of close collaboration in the new EU environment: A public affairs update

By Neil Betteridge, Public Affairs Strategic Advisor, and Gerd Burmester, International Liaison Officer, EULAR Public Affairs

EULAR’s commitment to collaboration as a means of hitting major targets which benefit the rheumatic and musculoskeletal disease (RMD) community is as strong in the area of public affairs as it is in any other. Whilst EULAR Study Groups and Task Forces bring experts together with a common goal on a range of clinical issues, so the Public Affairs Group fosters collaboration to change social and health policies.

“It’s an opportunity to promote the socio-economic inclusion of people with RMDs”

In this regard, 2019 is a hugely important year for the future of EU health and social affairs policies. The recent parliamentary elections and establishment of the new Commission represent an opportunity to consider the role of the EU in improving the health of EU citizens, but also in promoting the socio-economic inclusion of people living with RMDs and other chronic conditions.

To facilitate discussion on the future of EU health policies, EULAR organised its annual World Arthritis Day Conference in Brussels this October on “A sustainable and effective EU health policy for citizens: Focusing on chronic diseases and inclusion in social and economic life”.

The aim of the conference was to develop policy recommendations to EU and national policy makers on how to improve the effectiveness of health policies. In particular, the event focused on the contribution of health policies to facilitating the participation of people with RMDs and other chronic conditions in the labour market and in education. This aligns to our top strategic priority in public affairs: supporting more people with RMDs to obtain and stay in employment.

During the event, EULAR President Prof. Iain McInnes presented the EULAR Vision Paper on the future of European Health Policies. The document presents EULAR’s recommendations to improve the effectiveness of health policies in the coming years.

The document focuses on five main issues.

1. The EU needs to be more ambitious and show its commitment in the area of public health. For several years, the EU has been perceived as weak in ambition. Therefore, the new European Commission needs to strengthen support to Member States’ efforts in fighting chronic diseases and their socio-economic consequences. The new Commission should also listen to the demands of EU citizens. According to the Eurobarometer (March 2017), 70% of EU citizens think the EU should do more in the area of health.

2. It should make the old promise of “health-in-all-policies” a reality and ensure a good level of co-ordination between health and other policy areas. This is necessary to improve prevention and manage the economic burden of disease. This is particularly the case in employment and social affairs policies, where the prevention of work-related diseases – especially RMDs – could significantly help large numbers of people to remain active in the labour market.

3. The Commission should strengthen the impact of its health policies. An important aspect of this would be promoting the use of Health Impact Assessments to decide on priorities (prioritising the socio-economic impact of health interventions), but also defining more concrete, actionable strategies on major chronic diseases such as RMDs.

4. The EU should be more involved in improving access to quality healthcare. It should ensure that citizens in all regions enjoy equal rights when it comes to access to healthcare professionals. But it should also strengthen its support to Member States to develop integrated healthcare models and eHealth solutions to cope with the increasing burden of RMDs and other chronic conditions.

5. Finally, European health policy should assign a central role to patients and patient representatives, to ensure that the voice of people with conditions such as RMDs is well represented in all relevant decisions concerning health policies. “Nothing about us without us!” as PARE would (rightly!) say.

Based on discussions among the EULAR Public Affairs Group, we are convinced that these measures and priorities would help the EU become closer to citizens and demonstrate in sceptical times the added value it can bring through progressive and effective policies.
PARE promotes collaborative research

Maarten de Wit, PARE Study Group for Collaborative Research leader, outlines how people with RMDs contribute to EULAR Study Groups across the three pillars

The unique structure of EULAR as a collaboration between health professionals, rheumatologists and people with rheumatic and musculoskeletal diseases (RMDs) is not only reflected in the General Assembly and the EULAR Congress programme, it also impacts all components of the organisation including the EULAR Study Groups.[1]

PARE representative participate in disease-specific study groups like those for systemic lupus erythematosus (SLE) and osteoarthritis. They are also involved in study groups for clinical challenges such as cardiovascular involvement in inflammatory arthritis (CVIIA) and therapeutic drug monitoring of biologics. Traditionally, there is a strong collaboration of patient representatives in health professional in rheumatology (HPR) study groups, such as those for the non-pharmacological treatment of back pain in patients with chronic low back pain.[2]

**Patient Research Partners**

Within EULAR, we have coined the term Patient Research Partners (PRP) for patients who have been introduced to the basic principles of evidence-based medicine and clinical research. The term PRP emphasises their equal position in the study group or task force and the call to develop sustainable partnerships. PRPs are recruited through the EULAR PARE PRP network and through participating health professionals. The number of PRPs in study groups varies between one and four. For various reasons, the EULAR recommendations for collaborative research[2] suggest recruiting at least two PRPs. This not only increases the diversity of the patient perspective; it also contributes to patient organisation capacity building. Additionally, it reduces the risk of having no patient input in case one PRP has to cancel participation, and it enables PRPs to help each other in preparing for their role in the study group. Having a sparring partner increases their motivation and confidence.

**Enabling PRPs to contribute**

In many cases, the PRPs are experienced patient experts who feel confident to speak up on behalf of patients in international research initiatives. They are able to speak English and have learned to provide the patient perspective in a critically constructive manner. In case specific knowledge is necessary to understand the research agenda, health professionals in rheumatology need to help PRPs become familiar with the terms and concepts. Their role is to create a safe environment and enable PRPs to contribute to the study group. This might sometimes mean that group leaders have to address individual needs from the PRPs, solve practical issues or make other adjustments in the project.

**PARE study group for collaborative research**

In 2017, the Standing Committee of PARE established its first study group on collaborative research. The aim is to study the benefits, facilitators and limitations of collaborative research within EULAR projects. Its annual meetings are well attended, with an increasing number of researchers participating. The first three meetings focused on international research initiatives, the establishment of national networks of PRPs and the education of PRPs. Good practices have come from Europe, Canada (Canadian Arthritis Patient Alliance) and the United States (International Foundation for Autoimmune & Autoinflammatory Arthritis).

Elsa Mateus, Chair of the Standing Committee of PARE, comments: “The study group has evolved into a platform where PRPs and researchers can meet, learn from each other, discuss current challenges and prioritise research topics. It is a real example of success for collaboration and learning.”

**Online training course for PRPs**

Themes for future meetings are:

- the development of the EULAR online training course for PRPs under the EULAR School of Rheumatology
- opportunities to improve the dissemination of scientific knowledge among people with lower health competences.

The ultimate objective of the study group is to establish a community of practice comprising researchers and PRPs with an interest in developing new and innovative methods to make the voice of patients heard in rheumatology research.

HPRs can help to recommend patients for the PRP programme. For more information, contact Alzbeta Göhm in the EULAR secretariat at alzbeta.goehmann@eular.org

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The Paediatric Rheumatology European Society (PReS) is dedicated to improving the care, health and well-being of children and young people with rheumatic conditions. Jeanette Cappon, a paediatric physical therapist from Amsterdam, the Netherlands and health professional representative on the PReS Council, explains how health professionals are making a difference in paediatric rheumatology.

International and diverse leadership

The PReS Council comprises eight members who are elected for four years by the PReS members. Berent Prakken (NL), Michael Beresford (UK) and Angelo Ravelli (IT) are the executives. Jordi Antón (ES), Yozef Uziel (ISR), Fabrizio De Benedetti (IT) and Lovro Lamot (HRI), all medical doctors, represent respectively the education, clinical affairs, research and trainees committees to address areas of importance to PReS members. I have represented the health professionals (HPs) committee since September 2018.

My personal commitment is to bring – and keep – together a group of 40-50 HPs in paediatric rheumatology (PTs, OT, nurses, psychologists, social workers, podiatrists, sports scientists) together on a yearly basis at the congresses. In between, we work on projects. Until now there was only one person with an HP remit within PReS, but we will enlarge the HP committee by two more people. Wendy Costello (IE) is a co-opted member as the representative of ENCA, the European patient/parent organisation. Nicola Ruperto (IT), the chairman of PRINTO, is also a co-opted member of PReS Council. With the considerable overlap in the membership between these two organisations, this will help facilitate good clinical research.

Collaboration between PReS and EULAR

I feel a positive vibe within the PReS Council towards more collaboration with EULAR. There are already several connections. Tadej Avčin (SIL), head of the PReS Academy, is also chair of the EULAR Standing Committee on Paediatric Rheumatology. Lovro and Wendy work together with EMEUNET and PARE. PReS has had regular input into the educational/scientific programme of the annual meetings of EULAR, but this year we had the best integrated EULAR/PReS joint meeting ever in Madrid.

It was in Madrid that I met Tanja Stamm, your Vice President representing HPRs. We see several possibilities for future collaboration as we have overlapping themes like physical activity, pain and fatigue management, role of the nurse, transition and managing school and education situations.

Health professional input into PReS

An important task for HPs now is to suggest topics for our congress programme. HP and ENCA design a common session annually. Interactive workshops will be integrated into the programme where colleagues can find network partners with shared interests.

Since travel costs have been a barrier, PReS will endorse a certain amount of travel bursaries for its members. HP/researchers are encouraged to participate in the Young Investigator meetings which take place two days before the congress.

For more information, contact Jeannette at j.cappon@reade.nl.
Collaboration and partnership in knee and hip osteoarthritis research

Martin van der Esch, a physiotherapist from Amsterdam, the Netherlands, discusses the outcomes of his educational visit to Keele University in the UK in early 2019

My two-day visit was hosted by George Peat at Keele University and was made possible by a EULAR educational visit grant. It took place between 15-16 January 2019 and involved meeting 13 researchers from different disciplines to jointly present and discuss the work of three research groups:

(i) the Research Institute for Primary Care and Health Sciences, Keele University, Keele, Staffordshire, United Kingdom
(ii) the Amsterdam UMC, department of rehabilitation medicine and Reade Centre for Rehabilitation and Rheumatology Amsterdam, the Netherlands
(iii) the Centre for Health, Exercise and Sports Medicine, Department of Physiotherapy, The University of Melbourne, Melbourne, Victoria, Australia.

All groups presented existing and future research on three topics: 1) managing osteoarthritis (OA) in the context of comorbidity; 2) stratified care in OA; 3) management of hip OA.

The ultimate aim of this educational visit was to learn from each other's work, to encourage collaborative research and to identify and prioritise activities for future studies in OA. Six researchers came together from Reade Amsterdam (M. van der Esch, M. van der Leeden, M. de Rooij, A. de Zwart, J. Knoop and W. Lems), six researchers from Keele University (G. Peat, N. Foster, M. Holden, E.L. Healey, C. Jinks, J.G. Quicke) and one researcher from Melbourne University (K.L. Bennell). All participants are involved in OA research and the three main topics mentioned above. The group included workers in rehabilitation, rheumatology, epidemiology, psychology and physiotherapy and have an active interest in optimising the quality of studies in knee and hip OA, and implementing study results into primary and secondary care.

Exercise for osteoarthritis in the context of significant comorbidity

Since the number of comorbidities is rising in an elderly population, and since comorbid individuals have often no access to physiotherapy, comorbidity is a key-issue. This topic emphasises access to – and effectiveness of – exercise interventions for people with knee OA and significant comorbidity.

Evidence was presented from a completed randomised controlled trial (RCT) from Amsterdam on comorbidity-adapted exercise for OA patients with significant comorbidity, with a superior response in those with comorbidity versus controls, as well as a study proposal for peri-operative, comorbidity-adapted exercise therapy in patients with knee OA and comorbidity undergoing arthroplasty.
Discussions covered the barriers to translating intensive interventions in referral-based rehabilitation settings to national health service primary care where resources typically constrain the number of treatment sessions: in the Netherlands 12 weeks, in the UK 6 sessions. Thus, a new RCT on comorbidity in knee OA in the two countries in the current healthcare system is not possible. This discussion set the scene for a presentation on structured clinical reasoning for exercise prescription in patients with comorbidity. Structuring clinical reasoning can be important in the management of patients with a complex health status due to multiple chronic diseases and, more specifically, in OA-related comorbidity. The packaging of such structured clinical reasoning into training materials for physiotherapists and other healthcare professionals involved in the management of OA could be valuable for moving towards implementation.

Secondary analysis of pooled exercise RCT data might provide insight into whether comorbidity modifies the effectiveness of exercise therapy among trial participants to guide clinical decision making. However, in many trials the severity of the comorbidity is not measured, indicating that no relationship can probably be found. Ongoing work by Mel Holden and colleagues from Keele is analysing the combined data from three Keele-based primary care RCTs of exercise for knee OA: BEEP (Benefit of Effective Exercise for Knee Pain) trial, TOPIK (Treatment Options for Pain in the Knee) trial and APEX (Acupuncture, Physiotherapy and Exercise for Knee Pain) study, examining whether the effectiveness of exercise differs by presence of obesity, depression, and other comorbidities. This line of enquiry overlaps into use of large pooled RCT databases like the OA Trial Bank for differential effectiveness studies to inform future stratified care approaches.

**Stratified care**

In this session, the different underlying models of stratification were introduced (Table 1) providing a useful framework within which to consider the different studies being undertaken by each group.

STaRt MSK has adopted a more “risk/prognosis-based” approach to stratification, building on the success of STaRt Back for stratified care for low back pain (LBP). It aims to broaden StartBack from LBP to other common musculoskeletal symptoms, including joint pain attributable to OA. By contrast, a current individual patient data meta-analysis of RCTs of exercise for knee OA will use a data-driven approach to identify patient factors related to differential effectiveness of exercise therapy. The OCTOPUS study is an ongoing stratified care RCT which is based on earlier studies finding and replicating (cross-sectional) clinical subgroups in knee OA.

Discussion considered the relative merits of these approaches, the underpinning evidence for different strata, and balancing trial efficiency with the often-large sample sizes required. These types of trials would benefit from collaborative multi-centre recruitment. Co-ordinating capacity and suitable trial funding mechanisms are key challenges, but a useful step is to collect the measurements needed for each stratification approach in our future studies.

**Management of hip OA**

Our focus was the potential for collaboration on new trials of non-surgical treatment in hip OA given the dearth of research in this area compared to that of knee OA. The groups discussed their recent and ongoing RCTs of interventions for hip OA and related conditions. These trials collectively suggest that it is difficult to effect clear and sustained benefits in patient outcomes from treatment such as exercise therapy and an automated internet-based pain coping skills training programme. These results challenge the prevalent idea that strategies demonstrated as effective for knee OA can be assumed to have similar effects in hip OA. Moving earlier in the pathogenic pathway and opening the idea of the potential importance of aetiology/mechanism/phenotype, the UK FASHION trial of arthroscopic surgery versus conservative care for femoroacetabular impingement was presented.

Discussion about the optimal type and intensity of the exercise for hip OA led to the conclusion that the pursuit of a new intervention study into the effect of exercise in hip OA was not supported. Instead, there was support for the need to define meaningful subgroups within hip OA to better inform intervention development and to target care. Observational data from large-scale cohorts have underpinned this activity in knee OA and there may be a case for a similar effort in hip OA. As an action point, it was decided to first cope data available from existing studies in hip OA to assess the potential for secondary data analysis as well as the gaps that would need to be addressed through a new cohort study. This would need to build on, and complement, work already begun by international collaborators on OA cohort mapping and harmonisation.

**Future actions**

The presentations and outcomes of the discussions during my visit were shared with all health professionals at both universities. The future actions are being discussed at each university. They include:

- To inform each other about upcoming studies from the three research groups and possibly apply for a joint grant specifically towards a hip OA cohort, aimed at identifying subgroups/phenotypes.
- Topic comorbidity: re-analyse existing data with comorbidity as mediator or moderator of clinical outcomes in existing exercise trials.
- Topic stratified care: describe and validate the algorithm for the analysis of subgroups.
- Topic hip OA: describe the differences between hip OA and knee OA to emphasise that hip OA is not the same as knee OA and more specific studies on hip OA are needed.

The presentations and related discussions have been a source of inspiration and have established and expanded several collaborations.

A full list of references is available from Martin at m.vd.esch@reade.nl

10 educational visit bursaries are awarded each year. Information about how to apply is on the EULAR website.

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**Table 1. Models of stratified care**

<table>
<thead>
<tr>
<th>Model</th>
<th>Description</th>
<th>Study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Risk/prognosis</td>
<td>Matching treatment to patients’ risk of future poor outcome (e.g. persistent pain and disability, rapid worsening trajectory, surgery)</td>
<td>START-MSK (Foster et al)</td>
</tr>
<tr>
<td>Responsiveness to treatment</td>
<td>Matching treatment A to those who benefit most from treatment A</td>
<td>STEER-OA IPD (Holden et al)</td>
</tr>
<tr>
<td>Aetiology/ Mechanism/ Phenotype</td>
<td>Matching exercise treatment targeting pathology, causal factor or mechanism, modifiable factor, diagnostic phenotype</td>
<td>OCTOPUS (Knoop et al)</td>
</tr>
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</table>
Reaching out

EULAR continues to work towards growing its health professional network membership. We meet two well-established members to find out about their current priorities and how EULAR complements their work.

National HPR member organisations of EULAR:
Austria, Belgium, Croatia, Cyprus, Czech Republic, Denmark, Finland, France, Germany, Hungary, Ireland, Italy, Malta, Netherlands, Norway, Poland, Portugal, Romania, Serbia, Slovenia, Spain, Sweden, Switzerland, UK

Visit the EULAR Health Professionals’ website to find out how your country could apply for membership
eular.org/health_professionals_membership.cfm

Enabling the best care

By Malin Regardt, President of SveReFo in Sweden

SveReFo, the Swedish health professional in rheumatology (HPR) organisation, celebrates its 30th anniversary this year. It was founded in 1989 with the objective of enabling a joint forum for all the different professions working in the field of rheumatology in Sweden.

From the start, automatic membership to SveReFo has been given to members of professional physician, registered nurse, physical therapist, occupational therapist and social worker organisations. For a few years now, it has also been possible for those not included in these organisations to apply for SveReFo membership. All with a connection to care, research or education within the field of rheumatology are welcome.

“There is an emphasis on knowledge management care”

In Sweden, there is a big focus and emphasis on knowledge management care, and national working groups have been initiated to ensure good and equal care for all patients. This incorporates the journey that people with RMDs make through life from early symptoms and diagnosis to maintaining life despite disability – including the ability to work and have a good quality of life.

Health professionals in Sweden acknowledge the importance of collaborative work in Europe and the world to enable the best care for people living with rheumatic diseases. Within rheumatology, the diseases are relatively rare and a joint effort is needed. We can learn – and should learn – from each other.
The Norwegian Interdisciplinary Organisation in Rheumatology (NIOR) was established in 2008 as a national interdisciplinary network for health professionals working with rheumatic diseases. Currently, we have more than 250 members from all over Norway.

NIOR aims to contribute to enhancing interaction and development across professionals, as well as encourage research and dissemination of knowledge. To aid this, we have a Facebook group and a website.

In collaboration with the Norwegian Resource Centre for Rehabilitation in Rheumatology (NKRR) and the Norwegian Rheumatism Association, we arrange a national network conference in rheumatologically rehabilitation every second year. By being an active collaborator, NIOR can influence the content of this conference. In line with EULAR’s priorities, the overarching theme in 2019 was work participation and how to support a health-enhancing lifestyle. Furthermore, NIOR invites health professionals in rheumatology (HPRs) to present their work to improve clinical practice or research in an abstract competition. The abstract winner presents their work in a plenary session and is honoured with a scholarship covering the participation fee at the EULAR or PReS congresses.

In 2017, NIOR performed a two-stepped survey among our members about what HPRs consider to be core competences. The purpose was to develop an overview that could be useful in multidisciplinary collaboration, for new employees and the organisation of services. To our delight, the Norwegian work with core competences has been included in the recently-published 2019 EULAR Recommendations for the generic core competences of health professionals in rheumatology.

NIOR ambitions for the coming year are to continue being an active collaborator of the national network conference in rheumatologically rehabilitation and to enhance the dissemination of knowledge to facilitate HPRs to provide evidence based clinical care. Furthermore, we aim to improve our collaboration with both the rheumatologist and patient organisations.

It has been reported that Norwegian HPRs are relatively highly represented in the EULAR Study Groups. We can only speculate on the reason for this… Norway is privileged to have engaged HPRs and their work is acknowledged by both patients and rheumatologists. Furthermore, the Norwegian Resource Centre for Rehabilitation in Rheumatology performs research projects across Norway, which means that many HPRs have experience in participating in studies. In addition, it is easier to join if you know someone who has participated before.

If your country doesn’t have a national HPR association, EULAR can provide advice and guidance about forming one. Becoming part of the EULAR HPR network offers a wealth of opportunities to national health professional associations and their members. HPRs are vital to effective RMD care and research. Together we are stronger.

For further details, contact Rikke Helene Moe, Chair of the HPR Standing Committee. The application deadline is 31 January each year.

Visit eular.org/health_professionals_member_orgs.cfm for more information and to find a list of all member organisations.
EULAR HPR Study Group reports

The EULAR HPR Study Groups met face-to-face at the EULAR 2019 Annual European Congress of Rheumatology in Madrid. Here, the study group leaders provide feedback on their work.

**EULAR REST (RESEARCH AND STRATEGY) NURSES STUDY GROUP**

By Yvonne van Eijk-Hustings and Jenny de la Torre-Aboki, Study Group Leaders

This was the first REST nurses Study Group (SG) meeting following the merger of the EULAR Clinical nurses and the REST nurses SGs. Our research agenda topics are: optimising management (T2T, comorbidities); improving access to care; effective resource use/cost-effectiveness; improving patient outcomes; work/employment; self-efficacy/empowerment; different modes of care delivery; components of nursing knowledge. We also actively co-operate with other SGs, other EULAR activities – such as the Patient Education SG, EULAR HPR Online Courses, EULAR Task Forces – and ESNO (the specialist nursing organisation).

Several publications have been published by study group members during 2018/2019:


A EULAR HPR Research Grant proposal 2018 has been sent:

- Cost-effectiveness of nursing interventions in the care of patients with rheumatoid arthritis comparing basic and advanced practice in four European countries (Spain, Portugal, United Kingdom and Netherlands).

**EULAR Physical Activity and Exercise Therapy Study Group**

By Rikke Helene Moe, Study Group Leader, and Li Alemo Munters, Study Group Co-leader

With rheumatic and musculoskeletal diseases (RMDs) contributing to 30% of disability in Europe, our SG is discussing what we can do about it. Active members of the group are in touch regularly about our various projects to improve aspects of physical activity and exercise to benefit people with RMDs. Additionally, we have a network of almost 500 health professionals in rheumatology (HPRs) who are regularly kept up to date, and have the opportunity to input on projects, discussions and ideas within the group.

We are working systematically for high quality assessments, recommendations and implementations of physical activity and exercise therapy for people with RMDs. Furthermore, we facilitate, support and initiate clinical development, research projects, assessments and session proposals. At this year’s meeting, we discussed how best to implement the EULAR Recommendations for physical activity, including the increasing evidence that high intensity exercise may be even more beneficial for people with RMDs than the basic recommendation of 150 minutes activity per week.

Our session proposal working group will now focus on developing a proposal about how to make high intensity exercise happen and how its effects relate to clinical decision-making based on a combination of health, RMDs, comorbidity and personal factors. We are also adjusting our proposal for a more interactive session about how to avoid surgery in cases where rehabilitation and surgery are equally effective, as rehabilitation has less serious side effects and may be cheaper.

**EULAR Study Group on Patient Education (STOPE)**

By Mwidimi Ndosi and Heidi Zangi, Study Group Leaders

STOPE aims to promote excellence in patient education research, support the implementation of evidence and promote collaboration among professionals and patients interested in patient education. Attendance at this year’s face-to-face meeting during the EULAR Congress was good, with representatives from 13 countries – Belgium, Denmark, France, Germany, Italy, Japan, Norway, Spain, Sweden, Switzerland, Portugal, the UK and the USA.

The main agenda points were an update of the dissemination project (Dr. Mwidimi Ndosi) (see page 4) and future research priorities (all). Country champions had successfully translated the patient education survey into different languages, with the help of patient research partners. It was agreed that, after testing the survey, data collection should continue into September to accommodate the summer holidays. The next steps were discussed, including a publication strategy and authorship.

The Chair of this year’s meeting, Dr. Heidi Zangi, invited members to share their patient education research ideas and suggest ways in which STOPE could support them. Three members from Denmark, Germany and France discussed their current research interests. Members were encouraged to share research ideas and form working groups or collaborations.

With the conclusion of the current project, it is expected that future activities will focus more on other aims of STOPE including strengthening collaborations and updating the recommendations.
EULAR Non-pharmacological Treatment of Autoimmune Connective Tissue Diseases Study Group

By Carina Boström, Study Group Leader

This study group was approved by EULAR in spring 2019 and we had our first meeting at the congress in June. The overarching aim of the SG is to improve and standardise care and, thereby, reduce the variation in care of patients with connective tissue diseases (CTDs) within the EULAR member countries. The group has several objectives, some of which are mentioned here:

- identify areas where variation in care and rehabilitation exists for people with CTDs
- develop consensus-based and evidence-based guidelines for the care of people with CTDs through systematic reviews and EULAR-recommendations for non-pharmacological treatment in CTDs
- implement better evidence and standardised care pathways across EULAR member countries
- be a resource and provide feedback on EULAR HPR Online Courses on CTDs.

At our first meeting we discussed what kind of research/ projects were occurring among the participants at the meeting. Within the SG, there are members who have started working on a module about systemic sclerosis for the EULAR HPR Online Course. We decided that, in the near future, the study group will apply for a task force for EULAR recommendations of non-pharmacological treatment in autoimmune connective tissue diseases. Further, a virtual network for the study group will be created within LinkedIn during autumn 2019.

EULAR Foot and Ankle Study Group

By Lindsey Cherry, Study Group Leader

The Foot and Ankle Study Group – consisting of 37 members, from 11 nations and representing at least seven disciplines – has had a productive year. The highlight being the publication in *Musculoskeletal Care* of the group’s research project: “An international survey about the provision of rheumatic foot health care” led by Dr. Begonya Alcacer-Pitarch.

Having reached this milestone, the group will continue to study phase two. This will expand the international survey to include HPR and patient responses about RMD foot healthcare. There is currently an open call for anyone with an interest who may wish to join the project working group. Please email me at l.cherry@soton.ac.uk for more information.

Simultaneously, the group is developing a research proposal that focuses on international harmonisation of RMD clinical outcome measures for the foot and ankle, led by Dr. Gabriel Gijon. Anyone with an interest in the field who wishes to join this project working group is invited to email me.

Looking forward to 2020, the group has proposed a congress HPR session, led by Tiziana Nava, focusing on bio-psychosocial approaches to foot care, particularly for people with scleroderma.

The group, which meets virtually quarterly, is open to new members and warmly invites colleagues to get in contact for more information.

EULAR Work Rehabilitation in People with RMDs Study Group

By Yeliz Prior, Study Group Leader

It is important that HPRs prioritise work assessment and interventions in clinical practice to support people with RMDs who want to retain employment or return-to-work following sickness absence or job loss. This EULAR Study Group was born out of these principals and had its first meeting in Madrid, in June 2019. Twelve HPRs from eight countries attended the meeting where they discussed current projects in their respective countries, the potential for international collaborations to support current work and ideas for new SG projects. Funded by a EULAR HPR grant, there is ongoing collaboration between the UK, Sweden and the Czech Republic to develop and test Work Patient Reported Outcomes that are linguistically and culturally adapted. A further objective was identified: a collaborative approach to develop and test a standardised structured interview to help with goal setting and intervention planning to assist work rehabilitation.

Apply now: EULAR HPR research grant

Every year EULAR funds one health professional research project in the field of rheumatic and musculoskeletal diseases (RMDs) that is in line with the mission, objectives and goals of EULAR. Projects will be funded up to a maximum of EUR 30,000. Application is now open!

More information can be found on the EULAR website at eular.org/health_professionals_research_grant.cfm

The application deadline for the 2020 HPR Research Grant is 15 December.
Meet the national health professional delegates on EULAR’s HPR Standing Committee

There are 24 formally ratified EULAR HPR organisations represented by their presidents or other nominated officials on the EULAR Standing Committee of Health Professionals in Rheumatology.

The national HPR delegates contribute to shaping health professional activities within EULAR.

The Committee, headed by Chair Rikke Helene Moe, Chair Elect Ricardo Ferreira, EULAR Vice President representing health professionals in rheumatology Tanja Stamm and Vice President Elect Thea Vliet Vlieland, discusses ongoing projects and new proposals for the EULAR Executive Committee, initiates the health professional programme for the EULAR Annual European Congress of Rheumatology, and supports and reviews HPR membership applications.

Each year the Committee holds its annual meetings at the EULAR Congress. It has sub-committees and can also include other invited experts.

Rikke Helene Moe: rikmoe@gmail.com
Tanja Stamm: tanja.stamm@meduniwien.ac.at
Ricardo Ferreira: ferreira.rjo@gmail.com
Thea Vliet Vlieland: t.p.vliet_vlieland@lumc.nl

For contact details of all the member organisations and nominated EULAR liaison personnel, please visit the EULAR website to find the most up-to-date information.

www.eular.org/health_professionals_membership.cfm

Editorial office
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