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“During the economic recession price has become a decisive factor for rheumatological care.”

The Rheumatism Foundation Hospital was an important multidisciplinary research centre in Finland.

Picture source: YLE/Lahti

Musculoskeletal conditions and the media

The Bone and Joint Decade 2000–2010 (BJD) is coming to an end in a little more than six months. For almost 11 years in more than a hundred countries the BJD has attempted to highlight in various ways the burden of musculoskeletal conditions on the society. The impact of these conditions on national health and economy continues to be high. Thus the Decade will probably be continued. The International Steering Committee of the BJD aims at safeguarding the work carried out during the Decade e.g. by creating a data bank and organizing further projects for promoting musculoskeletal health on different continents. The title Bone and Joint Decades has emerged to replace the singular Decade.

How, then, could musculoskeletal conditions, their care and prevention have a bigger part in the public debate? Musculoskeletal disorders are not a hot topic, and they seldom provide the same elements of drama associated with many other ailments. Instead they are often considered as aspects of “old age feebleness” in a world that worships youth and youthfulness.

In the eye of the media

This year the Finnish media has voluntarily paid attention to musculoskeletal conditions twice. The first media buzz surrounded David Beckham’s decision to have his broken Achilles tendon operated in Finland. During the media fuss, musculoskeletal ailments, especially sports injuries, received their small share of the attention.

The second media debate has been a sadder one. The internationally renowned Rheumatism Foundation Hospital, founded in 1951, was declared bankrupt in March. The hospital that struggled against increasing financial difficulties for five years was cleared of its patients and staff in a few weeks. The situation came as a complete surprise to the patients and to the partners alike, let alone the general public. The hospital offered specialized multidisciplinary expertise, especially as regards advanced care of juvenile arthritis and demanding orthopedic surgery, practically not available anywhere else in Finland. A unique centre providing rheumatological care was lost.

In the media the bankruptcy aroused strong emotions and debate, not only to save the hospital but also to find culprits. The blame was put on hospital districts and on the Ministry of Social Affairs and Health since the services of the hospital were no longer needed as much as previously and on the Social Insurance Institution of Finland that bought less and less rehabilitation services as other service providers had emerged after competitive bidding. The bankruptcy also became an instrument in national politics. The parliamentary election is taking place next year, and the opposition submitted an interpelation question in the matter, to test whether the government enjoys the confidence of the parliament.

Suddenly rheumatic conditions were a hot topic in the media debates. But what was the cost of newspaper columns, radio broadcast or current-event TV exposure? I can only imagine the distress of the people with no knowledge of a future place of care or the concern about sufficient experience for, say, operating a hip that has undergone multiple surgical procedures. By the end of May the future care of all the former patients of the hospital, the actions by the hospital districts, and the care responsibilities to be undertaken by special resource centres should be settled. But time moves slowly when you are waiting.

Experience for future use

Perhaps something good has come out of this very unfortunate event. Rheumatological care has perhaps become a symbol of a broader debate about a citizen’s basic right to be ill safely in all circumstances. The care system should be organized in such a manner that experience is never solely dependent on a single operator. On the other hand, it is practical to centralize certain special expertise especially in countries with a small population such as Finland.

Private service providers supplement the public health care system, but especially when they sell services to the public health sector, their operation should be secured in such a way that patient safety is not jeopardized if the service provider must close down its business. The practical applications of EU competition regulations should also be discussed. Quality of care seems to be less and less important in the service provision. During the economic recession price has become a decisive factor. This is a great challenge to us all working in the field of musculoskeletal conditions. How could we determine a shared set of good European practices in which the significance of multidisciplinary teams in the care and rehabilitation of people suffering from musculoskeletal conditions is sufficiently taken into account in competitive bidding, to ensure that the effectiveness of care yields the best possible outcome?

Jaana Hirvonen
Editor, psychologist

Jaana Hirvonen works as the development director of the Finnish Rheumatism Association.
In this issue

This HP Newsletter is a special congress edition distributed in Rome. We will introduce a scale of topics on health professional work and research in the field of rheumatic diseases and musculoskeletal disorders.

In his article, EULAR President Paul Emery writes that he is a proud member of a multidisciplinary team and confident on the health professionals’ future prospects within EULAR. Vice-President Kåre Birger Hagen tells about health professional activities at the congress and invites each professional group to their own networking meetings. Chairperson Tanja Stamm highlights the member campaign for new national HP associations or leagues to join EULAR. Heidi Zangi writes about NIOR, the new member HP organisation from Norway.

We also have interviews with Jenny de la Torre who will discuss the recent developments of nurse’s role in the multidisciplinary team in Spain and Ingvild Kjeken exploring the research priorities of people with rheumatic diseases from a patient-centered point of view. According to Karin Niedermann, mixed research methods may be the way of the future health professional studies and Sarah Ryan gives valuable advice on how to publish a scientific article... to mention only a few themes of this issue.

Do not miss the news on EULAR grants for educational visits or for research projects.

Enjoy the Newsletter!
As the new president of EULAR, it is a pleasure to be writing about the future plans for health professional (HP) development. The programme of work for HPs has been designated a priority area for the next two years. With this in mind, it is hoped that a decision could have a significant impact on HP activities in Europe.

The role of health professionals
Multidisciplinary care is now recognised as one of the key aspects of management of patients of rheumatic diseases and it is time that this is provided in a more consistent and structured way. An important initiative is a survey that will be conducted on the role of health professionals, and a grant has been awarded to Jackie Hill and Tanja Stamm to undertake this. It is hoped that this survey will clarify the potential of health professionals and make sure there is a more even access to the professional skills across Europe. This will link in with an announcement of the declaration of rights of patients with arthritis which will take place in 2010.

Leeds as a multidisciplinary example
The link between academic and service provision is particularly relevant to the role of HPs. In my own unit in Leeds, we have 14 nurses and other health professionals such as occupational therapists, physical therapists, psychologists and podiatrists, engaged in research and academic work in addition to more than 30 nurses and HPs in purely clinical roles. The unit has a skills-based approach whereby those with the appropriate skills, irrespective of their designated title, provide service and research, and this is a model which we believe has been successful and one that may benefit from a more formal arrangement.

A particular example of the success of this is the integrated foot-health clinical service and academic programme. All staff is employed on joint National Health Service (NHS)/University contracts and this has created a centre of excellence providing a national service example. EU research has allowed the development of questions of greatest relevance to patients and the documentation of this ensures that patients receive best care. The academic group provides national training service through the British Society of Rheumatology co-ordinated courses.

The clinical gains
Nurse specialists represent the most significant interface with patients and with new guidelines treating to target and aiming for remission, the regular visits are going to be administered to a large extent by nurses working to predefined algorithms. The advent of biologics means that nurses now have highly specialised roles in nurse driven monitoring and advising on these complex therapies.

The clinical gains are very large with the opportunity to achieve remission with early therapy and minimize the use of drugs if patients are able to get into a healthy state. The bottom line of this is that there has never been a more exciting time to be involved in the multidisciplinary team and linked with the above mentioned declaration of rights for patients; hopefully we will see a major advance in Europe in the next two years.

Paul Emery
The EULAR President
Professor
Academic Unit of Musculoskeletal Disease Chapel Allerton Hospital
Leeds, United Kingdom

“There has never been a more exciting time to be involved in the multidisciplinary team.”

Dr. Jackie Hill is an expert in rheumatology nursing. She was one of the first rheumatology nurse practitioners in the UK and is now a leader in the field of rheumatology research.
Invitation to health professionals

In the last meeting, the EULAR Executive Committee decided to reform the name of the Standing Committee of the Allied Health Professionals by leaving the term “allied” out.

– It is a great honor for me and the Chairperson of the Committee Tanja Stamm to invite you all to our booth at the EULAR Congress in Rome, Kåre Birger Hagen says.

The health professionals’ booth is located in the EULAR Village in hall C9-5 to C11-5. The idea of the village is to group all EULAR social activities in the same location and to create a relaxed atmosphere for informal meetings. Most of the EULAR-related activities and sister societies will be displayed in the village.

National health professional member organisations of EULAR as well as the Association of Rheumatology Health Professionals (ARHP) from the U.S. present their activities at the booth. New national representatives from Europe can learn more about the ongoing member campaign, prescribe our Newsletter, and leave their contact information for further details.

– This year, we will also arrange informal grip strength measurement events at our booth. By these events we wish to demonstrate some of the activities usually performed by health professionals. We hope that many colleagues will take the chance to test their grip strength and we also intend to compile results for different categories, such as professional groups, nations and so on, Kåre Birger Hagen tells.

The yearly EULAR Congresses provide the best opportunity for European health professional researchers and colleagues to interact.

– It is a great honor for me and the Chairperson of the Committee Tanja Stamm to invite you all to our booth at the EULAR Congress in Rome, Kåre Birger Hagen says.

– After the approval of the General Assembly in Rome our official name will be EULAR Standing Committee of Health Professionals in Rheumatology, Vice-President Kåre Birger Hagen underlines.

In the previous EULAR Congresses, our booth has proved to be an excellent meeting point for health professionals and representatives of the Standing Committee, says Kåre Birger Hagen.

16–19 June 2010: The preliminary health professional networking programme

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<tr>
<th>Wednesday</th>
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<tr>
<td>08:00 – 09:00</td>
<td>Networking Meeting for Physiotherapists in room 7E</td>
<td>08:00 – 09:00</td>
<td>Networking Meeting for Social Workers in room 7E</td>
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<td>09:00 – 10:00</td>
<td>Networking Meeting for Occupational Therapists in room 7E</td>
<td>09:00 – 10:00</td>
<td>Networking Meeting for Psychologists in room 7E</td>
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<td>Welcome to the booth:</td>
<td>Lunch break: Coffee and beverages available at the booth. Test your grip strength!</td>
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<td>10.30 – 12.00</td>
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<td>hall C9-5 to C11-5 Learn more about health professional activities and test your grip strength!</td>
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<td>Please notice also the HP Scientific Programme and the poster presentations</td>
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<td>16:30 – 17:00</td>
<td>Informal get-together at the booth</td>
<td>17.00 – 18.00</td>
<td>Networking Meeting for Nurses in room 7D</td>
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Casual meetings for HPs

– As usual, there will be Networking Meetings for the different professions which coincide with the Scientific HP programme of the Congress. We have organized the meetings in their own locations with better facilities for a get-together. Please see the timetable of the Networking Meetings below.

– You do not need to register in any way; you can just come and meet others, Kåre Birger Hagen advises.

This year new professional groups such as social workers have their own Networking Meeting.

– Please take advantage of this special occasion. It would be fantastic to see as many of you as possible, says Kåre Birger Hagen.

See you at the HP Booth in hall C9-5 to C11-5!
Interdisciplinary health professional organisations specialized in the care and treatment of rheumatic and musculoskeletal diseases in European countries are welcome to join in.

– So far, EULAR has five health professionals associations as members. In 2006, the first two national organisations requested membership of EULAR and were accepted. The Committee has also co-opted members from many European countries planning to establish a national HP organisation in the near future, says Chairperson Tanja Stamm.

The five health professionals associations are the British Health Professionals in Rheumatology (BHPR), the health professionals in rheumatology Switzerland (hpS), the Netherlands Health Professionals in Rheumatology (NHPR), the Swedish Rheuma Forum (SveReFo), and the Norwegian Interdisciplinary Organisation in Rheumatology (NIOR).

– New national members are more than welcome to join in. We try to make the process of becoming a member as easy and flexible as possible, Stamm assures.

One health professional association per country

According to the EULAR bylaws, only one health professional association or respective league from each country can be admitted as an official member of EULAR.

– A national health professional organisation may be recognised as such if it is autonomous and has a governing body with an Executive Committee and Board of Directors, Stamm tells.

A health professional association may not be a sub-division of the national scientific organisation.

If applications for affiliation are received from more than one organisation in a country, the organisations must come to an agreement as to which one of them shall become a member of EULAR.

– Several national organisations may also establish a joint association, enabling such an association to become an official member of EULAR, Stamm suggests.

The HP member campaign 2010

The Standing Committee of HPs continues the campaign promoting the national health professional (HP) organisations’ interest in becoming a member of EULAR and participating in the work of the Committee. The member campaigning will be highlighted in the EULAR Congress in Rome.

Will your national HP organisation be the next member?
Six steps to get involved for a national HP activist:

1. If a national interdisciplinary health professional organisation already exists in your country, please find out first whether there is a formal member representing this organisation at the EULAR Standing Committee of HPs. If so, please contact this person regarding your involvement in EULAR. You will find the member list of the Committee at www.eular.org/st_com_health_professionals.cfm.

2. In case there is no organisation representing health professionals in your country, you can establish a national organisation first. Bear in mind that this organisation’s bylaws should be in accordance with the EULAR bylaws. The EULAR bylaws can be obtained from the EULAR Executive Secretariat, contact: eular@eular.org.

   Importantly, this national organisation should represent different health professional groups (such as nurses, occupational therapists, physiotherapists, podiatrists, nutritionists, social workers, psychologists, and others) and should have a clear multi-/interdisciplinary perspective. All the professional groups mentioned above do not have to be represented in the organization, but an open attitude towards all health professionals in the organisation is required.

3. Fill in the application form which you can also obtain from the Secretariat together with a letter stating that your organisation wants to join EULAR as a health professional organisation representing your country. Submit this application form to the EULAR Secretariat. The General Assembly meeting once a year before the annual EULAR Congress in June will put your application and acceptance within EULAR to the vote.

4. When your organisation is a formal member, the person representing this organisation will also have a right to vote in the General Assembly.

5. The chairperson of the national organisation is commonly the representative as formal delegate member in the EULAR Standing Committee of HPs.

6. In the process of establishing a national organisation and even before this, the Committee welcomes any health professionals interested in founding a national organisation to become a co-opted member in the EULAR Standing Committee of HPs. As a co-opted member you are then welcome to participate in the meetings of the Committee and in other activities within EULAR. In this case, please contact the Chairperson of the Committee, Dr. Tanja Stamm: tanja.stamm@meduniwien.ac.at.

Reasons for becoming a member of EULAR

The main function of the EULAR Standing Committee of Health Professionals in Rheumatology is to endorse multidisciplinary collaboration in the treatment of rheumatic and musculoskeletal diseases in Europe. The Committee was established in 1989 as a European platform for cooperation and shared information among the different health professionals working with rheumatology. The Committee encourages health professional research in rheumatic and musculoskeletal diseases and works also to improve the patient’s role as the key expert of his/her own treatment.

As a member you can:

- interact with colleagues
- follow and participate in the development of health professional research
- learn about the recommendations on the best possible care and treatment
- organise or participate in health professional educational courses
- be part of a European health professional network with connections to other national HP organisations.


Introducing a new co-opted member of the Committee

I am very glad to be part of the EULAR Committee of HPs as a co-opted member. It’s been almost a year since I was welcomed by everyone to the Committee.

For four years, I have been working at the Cyprus League Against Rheumatism (CYPLAR). It is a patient organisation and a member of PARE. At the beginning, since I am a psychologist, I worked as a psychosocial support officer and the past two years I have been the director of the league.

Being part of the Committee gave me a chance to meet other health professionals working with rheumatic diseases and a possibility to “return” back to psychology in a sense. I was able to take part in the survey for the extended roles of HPs and I am as well in the Edgar Stene Prize Jury Committee representing the HP Committee.

What more do I expect from the HP Committee? Well, to learn more and gain knowledge that will help me to become a better psychologist and that will assist me to perform my job in the Cyprus League the best I can. My personal goal for next year is to build up an HP organisation in Cyprus with other local health professionals.

Maria Mathiou
Director (psychologist)
The Cyprus League Against Rheumatism

Co-opted members preparing for membership

The current national representation in the EULAR Standing Committee of Health Professionals in Rheumatology. The representatives of the co-opted member countries (marked with green on the map) can be contacted for further discussions on building a national organisation.
The Norwegian Interdisciplinary Organisation in Rheumatology (NIOR) was established in 2008 and admitted as an official member of EULAR in 2009. All health professionals working in the field of rheumatology in Norway are welcome as members. In mid-March 2010, NIOR had 170 members from all over Norway, including nurses, physicians, physiotherapists, occupational therapists, social workers, psychologists, pharmacists, health secretaries, and a patient representative.

For the next two years, NIOR aims at further developing the interdisciplinary network by interactively using e-mail (nior@ gmail.com) and website (www.nrrk.no) for exchanging information. Every two years, NIOR will arrange a national conference which focuses on challenges and new knowledge within the multidisciplinary field. The first conference was held in November 2009. Before the conference, we announce a grant for the best project presentation. The 2009 grant was won by Occupational Therapist Aase Skarboe for her presentation “Empowerment strengthens patients’ ownership of life” and it will give her the opportunity to attend the EULAR Congress 2010. We think that this kind of financial support is a way to encourage multidisciplinary research activity and dissemination. On the EULAR Congresses in Paris and Copenhagen, NIOR invited all Norwegian delegates to join a network meeting. These meetings have been much appreciated and we will continue the meetings at the Congress in Rome.

NIOR’s main goals are:
- to be a national multidisciplinary information network
- to establish new contacts and contribute towards collaboration between health professionals
- to encourage research activity and dissemination
- to increase health professionals’ influence in EULAR
- to encourage international collaboration

NIOR’s board is composed of five members elected for two years and representing different professions and institutions. The board consists of (first on the left at the top) Social Worker Anne Tovik, Occupational Therapist Solvaar Reinsberg, Physiotherapist Mona Røisland and (in front from the left) Nurse, Chair of NIOR Heidi Zangi and Nurse Bente Hamnes.

Health Professional influence
Another objective for NIOR is to strengthen international collaboration and the influence of health professionals within the EULAR organisation. For the last years, Norway has been represented with an increasing number of health professionals’ presentations at the Congress. We will work to maintain the representation and to encourage professionals from more rheumatology centers in Norway to submit abstracts. Our aim is that the health professionals’ presentations at the EULAR Congresses shall reflect the great variety of multidisciplinary work in the field of rheumatology.

Financial support
So far NIOR’s economy is based on one-time grants from Diakonhjemmet Hospital, Lillehammer Rheumatism Hospital and from the Norwegian Rheumatism Association. We charge no membership fee, so it is a continuing challenge to obtain financial support.

Heidi Zangi
Nurse, Chairperson of NIOR
Member of the Scientific Sub-committee of HPs
Heidi.Zangi@diakonsyk.no

Please visit our website at www.nrrk.no.
Health professional educational visits

Ever wanted to see how health care services, methods of rehabilitation or scientific studies are carried out in other European countries?

EULAR awards up to 10 bursaries for educational visits to health professionals other than physicians working in the field of rheumatology to enable them to visit colleagues in another EULAR member country.

– The amount of each bursary is between € 750 and € 1500. The total annual amount granted is € 7,500, says the Education Programme Coordinator Caroline Pasche.

The objective is to improve the standard of research and care and to foster collaboration across clinical units in Europe.

– This year we received six applications for a visit. We encourage health professionals to use this great opportunity to widen horizons in the professional sense, Pasche continues.

Ever wanted to see how health care services, methods of rehabilitation or scientific studies are carried out in other European countries?

– It has been stated repeatedly in the educational visit reports that the trips have been very rewarding for both the visitor and the hosts, assures the Education Programme Coordinator Caroline Pasche.

How to apply?
The deadline for applications is the 31st of March 2011. Applications for 2011 should be e-mailed to Ms. Caroline Pasche at the EULAR Secretariat (caroline.pasche@eular.org).

– Applications should include a CV with the date of birth, objectives of the educational visit, a budget, a written confirmation from the host hospital or institute, and the tentative time frame of the training visit, advises Pasche.

Recipients are required to submit a report to the EULAR Secretariat after the visit, focusing on the results that have been achieved.

– Only a short, one-page overview is required which may be published in the HP newsletter, Pasche tells.

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Example of a report

Educational visit that paid off
In 2008, I had the pleasure to receive an Educational Visit Grant from EULAR which I used to visit the Sint Maartenskliniek in Nijmegen, the Netherlands.

Objective of the visit
My supervisor Wim G.J.M. van Lankveld kindly offered me the possibility to participate in two sessions of the patient education programme for Systemic Sclerosis (SSc), to meet participants of the intervention programme and to meet staff members of the research team and therapists such as psychologists, rheumatologists and a social worker. I learned a lot about the background, procedures and content of current multidisciplinary patient education programme for patient with SSc at the Sint Maartenskliniek.

Furthermore, I was able to learn and talk about an ongoing longitudinal cohort study in patients with SSc conducted in the Netherlands. We also discussed possibilities to participate in an international study about the effect of a tailored intervention of patients at risk and discussed about its feasibility in our institution in Vienna.

Bettina Bauernfeind (on the left) and Wim G.J.M. van Lankveld enjoyed an evening together with health professional colleagues. Bettina Bauernfeind found that the procedure of applying for an educational visit grant was easy and that the visit was worth-while.

– I warmly recommend the grant for other health professionals, she says.

Report quotes:
“...this great journey acted as a stimulus for future research. It was an inspiring, motivating and stimulating educational visit. My personal goal to overcome my fear in speaking English was also achieved.”

Nurse, PhD from the Netherlands visiting Bristol Royal Infirmary in Great Britain

“I learned about unstudied areas in the health care research. I was encouraged to go on with the research I am involved in. I will bring several ideas back to Sweden.”

Physiotherapist from Sweden visiting Leiden University Medical Center in the Netherlands

The application form and the contract to be signed with terms and conditions are available at: www.eular.org/health_professionals_educational_visits.cfm
The link between professions

Quite often nurses volunteer as a liaison between health professionals of the rheumatology department.

– The tight schedule of the drug treatments offers a possibility to supervise the whole well-being of the patient. During these procedures, nurses may detect changes which require special attention and refer the patient to the appropriate member of the multidisciplinary team, explains de la Torre.

In her experience, nurses are typically the ones to notice, for example, symptoms of patient’s psycho-social distress related to the disease, the worries on disability, or family burden.

– Among other integrated roles, counselling is part of nurses’ responsibilities in cooperation with a psychologist. Since nurses consider patients from a holistic view, we are able to assess more or less all patients’ needs, de la Torre notes.

From the rheumatologist perspective, nursing clinics can help in the medical clinics chaotic accumulation of tasks by functioning as a complementary aid in the follow-ups of patients. In de la Torre’s opinion, nurses could take even a larger responsibility in the queue management. Specialized nurses could, for instance, renew drug prescriptions.

– Taking into account the positive feedback from my European colleagues, I do agree that nurses could get limited rights to prescribe medicines to patients after a proper training, de la Torre estimates.

Educational interventions

SER recommendations stress that nurses should be allowed to have an interactive role in the patient education (PE) based on the individual’s rheumatic disease and his/her personal circumstances. PE increases patient’s know-how on methods of improving behavioural habits and the scale of possibilities for self-management.

– The PE is not only about giving information, but also offering tools for acknowledging what to do in specific situations such as when the joint pain takes a sudden turn for the worse, de la Torre says.

There are several PE optional settings from individual, group interventions for patients and/or family members to community interventions, for instance, in patient associations or in health centres.

– These interventions are mutually rewarding since people with rheumatic diseases equally educate us by offering their own experience-based knowledge for our professional disposition, de la Torre finds.

Visit:

the website of Nurses Working Group of the Spanish Rheumatology Society (GTESER) at: http://www.ser.es/geser/

the Health Professionals from the Spanish Rheumatology Society at: http://www.ser.es/investigacion/Grupo_Trabajo/Aeproser.php

For further information, please contact: Jenny de la Torre Rheumatology Nurse Specialist delatorre_jen@gva.es

Following the model of the other European countries, the professional status of a Spanish nurse has changed in the recent years from a relatively unrecognized provider of health care into an active player of the multidisciplinary team. Traditionally, nurses have had precise roles in the paediatric unit, intensive care, or even in the treatment of diabetes. It is self-evident that the complexity of rheumatology demands for holistic, well-specialised nurses.

– As a matter of fact, nurses have always been vital; now our role is only becoming explicit. Fortunately, rheumatologists are more aware of our capacities, and many units have hired specialised nurses. Although units may have different approaches, we gain more experience in collaboration and our roles become more clearly defined. Efficient teams require time to grow, says Jenny de la Torre, who has worked as a nurse specialist for the past ten years at the Rheumatology Unit of Alicante University Hospital.

The Spanish Rheumatology Society (SER) recommends having nursing clinics in each rheumatology outpatient unit, or at least one nurse for every three rheumatology clinics.

– New, better-targeted therapies for rheumatic diseases have modified the role of nursing and caused a necessity of diversely skilled nurses, not only for the crucial administration and management of care in general, but also for drug monitoring, running tests, questionnaires and phone help lines, evaluating clinical outcomes and assisting in the physical assessment – in cooperation with other health professionals of course, de la Torre sums up.

The Spanish multidisciplinary care approach has demonstrated promising outcomes in the treatment of people with rheumatic diseases. Each health professional team member has a defined and integrated role. In this interview with Jenny de la Torre, we will concentrate on nurses specialised in rheumatology.

– We have experienced a tremendous development recently in some of the units, but still changes need to be done. Some Spanish outpatient rheumatology clinics still do not have any nurses – specialized or not – for the care and management of patients. Furthermore, it would be helpful to have a EULAR health professional recommendation indicating which training is necessary for a basic and advanced practice in rheumatology nursing and what are the formal training requirements, Jenny de la Torre suggests.

Picture source: Jenny de la Torre
To further develop multidisciplinary educational programmes in rheumatology, the Standing Committee of HPs has designed a Teach-the-Teacher course especially for physiotherapists, nurses, and occupational therapists.

The first pilot Teach-the-Teacher course was held in 2008 in Leiden, the Netherlands. Former HP Chairperson John Verhoef and former Vice-President Peter Oesch acted as the leaders of the programme.

In October 2009, Ms. Jana Korandová organised a similar course concentrating on the management of rheumatoid arthritis (RA) and osteoarthritis (OA) in Brno, Czech Republic. She will present a detailed abstract on the results of the course at the EULAR Congress in Rome.

There are plans for new Teach-the-Teacher courses in the near future.

Workshops and practical training were an essential part of the Teach-the-Teacher programme in Brno. The HP newsletter will tell more on the course in the coming issues.

Picture source: Jana Korandová

Honorary member of EULAR, Chief Nurse Jana Korandová (standing on the left) has a vast experience in organising EULAR courses for health professionals.

Picture source: Jana Korandová
In a recent study based on surveys, Ingvild Kjeken and her colleagues explored the research priorities of Scandinavians with rheumatic diseases. The study captures aspects of health and functioning that the people with diseases consider being important and reveals experiences and attitudes concerning participation in research projects.

Patient-centered research designs are considered very trendy, if not a must.

– However, those who live with a rheumatic disease or condition still have limited influence when it comes to setting the research agenda, says Ingvild Kjeken.

Health research has always depended on the patients’ willingness to volunteer as participants in studies. Nowadays, one can sense that there is a growing understanding among health researchers that patients should be involved as partners in research.

– Motivated participants are likely to enroll again and give enthusiastic feedback to those considering participation for the first time, thinks Kjeken.

The study is based on results from three surveys organised by the Rheumatism Associations in Denmark, Norway, and Sweden.

– The Scandinavian surveys demonstrate that people with rheumatic diseases respond positively to participating in research and are highly competent at identifying important research issues, Kjeken says.

Mutual interests among participants and researchers

The study shows that participants had similar priorities for research.

– As expected, the underlying reason for willingness to participate was the aim of the study. In general, etiology, prevention, early diagnosis, and new treatments were the most frequently chosen research topics, says Kjeken.

More than 90 percent of the survey participants indicated they would participate in studies on physical activities and exercising, diets, and physical therapy. Approximately half were willing to enroll in studies on medications or psychological interventions.

– Interestingly enough, there were differences among the diagnostic groups, as participants with rheumatoid arthritis (RA) gave highest priority to research on medications, whereas participants with osteoarthritis (OA) gave highest priority to research on physical exercise, Kjeken points out.

Occupational Therapist, PhD Ingvild Kjeken is a senior researcher at the National Resource Centre for Rehabilitation in Rheumatology, Diakonhjemmet Hospital, Oslo, in Norway. Her special research interests are user participation, functional assessment, and rehabilitation in rheumatology. Currently, she is engaged in a project in which the aim is to develop a methodology for involvement of patient representatives in research, and in studies evaluating the effect of rehabilitation interventions for people with ankylosing spondylitis or hand osteoarthritis.

For the most part, it seems that participants and researchers share virtually the same areas of interest.

– For example, improving the amount and quality of research on pain has been one of the highest concerns among people with RA and OA. We can safely say that the development of effective strategies aimed at pain relief and coping should have a high priority among health researchers. Then again, in the Norwegian survey, fatigue was the second most frequently listed topic for research on disease consequences, says Kjeken.

It should be noted that same areas of interest are of course more demanding from the researcher’s point of view.

– Many participants chose topics where the scientific evidence is conflicting, such as nutrition and alternative therapy. We can conclude that more studies are needed to allow people to make informed choices regarding the use of these therapies, she continues.

The ability to work was one of the major interests. The Norwegian survey participants' still working chose research on workability three times more frequently than those who were out of work, and a greater proportion also prioritized research on exercise.

– This indicates that people with rheumatic diseases have a strong motivation to stay in the workforce and may be interpreted as a call for action plans to enable them to do so, Kjeken underlines.

Breaking barriers

The ability of the health researcher to establish a friendly working relationship with the patient is an eminent factor enhancing participation. Building trust with the participants is quite a relevant part of the research process.

– This kind of trust may easily be broken due to misunderstandings of the extent, time, and inconvenience of the research-based tasks. For instance, feeling that the research did not come up with new knowledge can well lower the eagerness to participate in future projects, Kjeken tells.

Painful procedures, time consuming trials, travel distance and expenses, and
problems taking time off from work were often noted as demotivating factors.

– Furthermore, personal embarrassment caused by a need to reveal intimate information or to expose body parts may be an important barrier against a research trial, says Kjeken.

A relaxed atmosphere would enhance the willingness to participate in studies to come. Many respondents also emphasized that researchers should understand that living with a disease is an individual experience, and that the patient is the one with the most reliable knowledge about his or her situation and symptoms.

– Naturally, everyone wants to be regarded as an individual with expertise rather than as study object, Kjeken adds.

Researchers should openly discuss mutual expectations and be ready to adapt time schedules and procedures to participants’ needs as much as possible.

– Efforts should be taken to minimize the number of separate tests and questionnaires which people need to complete to avoid unnecessary waiting and extra trouble, says Kjeken.

Guidelines should be followed

Providing automatic feedback on study results would increase the willingness to participate in future studies. Research projects should include a communication plan for dissemination of the results to the participants and their families and the patient population concerned. It is essential that the findings are made available in formats and in general language that all can understand.

– Many researchers support the practice of providing research participants with feedback. Still, the results from the Danish survey demonstrates an inconsistent practice, as only half of those who had participated in studies had received any feedback of the study results, Kjeken says.

To improve future practice, existing guidelines for provision of study results should be followed. These guidelines include offering research results at the time of study enrollment, disclosure following peer review but prior to public disclosure, and presenting participants with the harms and benefits of receiving the results. Budgeting for the costs, including maintaining contact with research participants, is important.

– Involving patient representatives as working partners in research projects is an effective method to ensure patient-centered research. We have experienced that collaborating with patient representatives resulted in additional research questions that very highly relevant, as well as in a more patient friendly design. Consequently, the inclusion of patients in the study has been running very smoothly. We therefore recommend this as a procedure to be adapted by all health scientists, Kjeken advises.

Read the whole research article:

Mixed methods offer new ways in health professionals’ research

Mixed methods refer to the combination of qualitative and quantitative research approaches and aim to take advantage of both. Mixed method designs are an option to improve the understanding of a phenomenon under research.

Mixed method studies have become increasingly popular in health sciences during the last two decades. The Cinahl database shows that there were almost 2700 publications from 2000 to 2010, including 70 in the first trimester of 2010, compared to approximately 500 from 1990 to 1999. The first paper was published in 1986. The papers in the 1980s (less than 20) marked the beginning of a new scientific era of combining methods to enrich the avenues of research.

A mixed methods approach may enhance the completeness and value of a study. Particularly, including qualitative (QUAL) approaches facilitates the inclusion of the patients’ perspective in a more in-depth manner. However, the decision to combine methods should not be based upon a “more methods, the better” thinking, but a solid rationale justifying this strategy.

The history of methods
From the 19th century until after World War II, research in human sciences preferred experimental or quasi-experimental designs. Consequently, this period was dominated by a quantitative (QUAN) research paradigm, called logical positivism. After World War II, the extreme axioms of logical positivism were increasingly criticized. The further development towards post-positivism and more radically, the emerging of a novel QUAL approach known as constructivism, were the answers to the widely discredited axioms of positivism.

A period of purism followed, where it was appropriate to either use QUAL or QUAN methods and there was in fact a paradigm war about the truth of the underlying axioms, which was advocated by purists until the mid-1980s. At that time, influential researchers (e.g. Howe) started to counter the incompatibility thesis of the “paradigm warriors” and the paradigm-method link and postulated “pragmatism” as a new paradigm. The pragmatic approach argued that QUAN and QUAL methods were compatible. The pragmatists pointed out that the differences between the methodological approaches had been overdrawn and they advocated with good reasons for a co-existence of the two paradigms: both had been used for years and, supported by funding agencies, both had influenced policies, and both have provided new knowledge.

QUAN and QUAL
Mixed method studies combine QUAN and QUAL approaches into the research methodology, either within one paradigm and/or between the paradigms. As a further step, mixed model studies mix aspects of the paradigms in all or many steps of a research process.

The use of mixed methods within a study can be basically equivalent or one paradigm dominates the other. In both situations, the methods can be used in sequence or parallel/simultaneously. The sequential design takes into account the findings of the previously applied method, whereas in the simultaneous approach, the two methods are applied at the same time and combined in the analysis phase only.

Table 1 lists some of the benefits and disadvantages of mixed approaches. There are many reasons for choosing a mixed methods approach, however, again it should be emphasized that it is the research questions and hypotheses that drive the methods applied.

References and sources:
2. CINAHL® is the Cumulative Index to Nursing and Allied Health Literature, is the most comprehensive resource for nursing and allied health literature available at www.ebscohost.com/cinahl.

Karin Niedermann will defend her doctoral thesis on “Aspects of Joint protection education in people with rheumatoid arthritis” at the University of Maastricht in July 2010. One of her studies examined the perceptions of people with RA and occupational therapists towards joint protection behaviour by means of a mixed methods approach. Her main research interests are patient education and behavioural change in chronic disease, mainly rheumatic diseases and diabetes; physical activity in chronic disease and prevention; development and testing of assessments and questionnaires, including Item Response Theory (IRT) and Rasch Analysis; clinical quality management.

Picture source: Karin Niedermann
Triangulation techniques
In the analysis phase, the use of mixed methods is always linked with using the so-called triangulation techniques. Triangulation refers to the combination of two or more methodological aspects of research to find convergence in the results and possibly strengthen the interpretation of findings. The definition of “triangulation” originates from trigonometry in which it is used to determine an unknown point or location by two fixed points in a known distance apart, thus that all three points together form a triangle. According to Denzin (1978), there are at least four basic types of triangulation: 1) Methodological triangulation: involving multiple methods to study a research problem. This can include multiple methods within the QUAN or QUAL approach or across the QUAN/QUAL approaches. 2) Data triangulation: using different data sources (statistics, interviews, observations, questionnaires, and documents, etc.), 3) Investigator triangulation: using different perspectives or multiple researchers in an investigation, 4) Theory triangulation: involving more than one theoretical perspective or hypothesis to interpret the results of a study.

Mixed methods provide convergence and “a bigger picture” of the results that are beyond triangulation, such as complementarity, allowing to examine the overlapping or different facets of a phenomenon; initiation, by detecting paradoxes, contradictions or fresh perspectives; development, where the results from the first approach applied help to choose the second method (i.e. sequential design); and expansion, by adding complexity, breadth, and scope to a project.

There is now a wealth of methodological options and perspectives to choose or combine together. There is no longer a need to be a “prisoner” of one method only. Mixed methods examine the same general problem by posing specific questions from different approaches. This may provide new perspectives, enhance validity of the results and increase the overall meaning of a project.

Karin Niedermann, MPH, BScPT
Physiotherapist, Head of MSc Programme, Senior Research Fellow, Institute of Physiotherapy, University of Applied Sciences, Winterthur, Switzerland and Department of Rheumatology and Institute of Physical Medicine, University Hospital Zurich. karin.niedermann@zhaw.ch

Table 1: Choosing a mixed methods approach

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<tr>
<th>Type of triangulation</th>
<th>Benefits</th>
<th>Disadvantages</th>
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<tbody>
<tr>
<td>Methodological triangulation</td>
<td>Confirmation (convergent validity), capture completeness</td>
<td>No rescue of flawed study</td>
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<tr>
<td></td>
<td>Comprehensive view</td>
<td></td>
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<tr>
<td>Data triangulation</td>
<td>Different nature and amount of data</td>
<td>Amount of data, time needed for analysis</td>
</tr>
<tr>
<td>Investigator triangulation</td>
<td>Improves validity (decreases potential bias)</td>
<td>Investigator biases may be difficult interpretation</td>
</tr>
<tr>
<td></td>
<td>Adds different perspectives</td>
<td></td>
</tr>
<tr>
<td>Theory triangulation</td>
<td>Challenges obvious explanations and competing hypothesis, premature interpretation</td>
<td>Lack of rationale for mixed methods</td>
</tr>
<tr>
<td></td>
<td>Theory based conflicts (no framework to fit)</td>
<td></td>
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</tbody>
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An example of mixed study on joint protection
In a mixed methods study, the benefits and barriers of joint protection (JP) behaviour in people with rheumatoid arthritis (RA) were evaluated by using questionnaires with RA participants and occupational therapists (OTs) and focused interviews with RA participants. The aim was to understand the phenomena of JP behaviour from patients’ and therapists’ perspectives. The mixed methods approach that combined the quantitative data and the qualitative data, allowed obtaining a more comprehensive view.

Mixed methods | Gain |
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<tbody>
<tr>
<td>Use of mixed methods/methodological triangulation</td>
<td>More comprehensive view patients’ and OTs questionnaire ratings on a “general level” whereas interviews reflect the patient’s everyday experience</td>
</tr>
<tr>
<td>Use of investigator triangulation</td>
<td>Interview analysis by three researchers with different professional background (physiotherapist, occupational therapist, rheumatologist)</td>
</tr>
</tbody>
</table>

References and sources:
There have been many exciting developments in rheumatology over the last decade including new roles with the creation of consultant nurse and health professional (HP) posts and HP research continues to flourish. This has resulted in interesting clinical, professional and research activities to write up for publication.

Why should we be encouraging health professionals to publish? Firstly, through sharing research findings we can disseminate new knowledge to a vast number of people nationally and internationally. Jackie Hill's seminal paper on the role and effectiveness of the clinical nurse specialist was instrumental in the development of senior nursing role within the United Kingdom and beyond. Also work by Kate Lorig and her colleagues in America has lead to the Arthritis Self-Management Programme being implemented in many countries around the world, thus contributing to the collective body of rheumatology knowledge.

A second reason is that publishing our professional and research activities provides a source of reference as it records what we as health professional are thinking, debating, and developing. For many years, nurses and HP's prescribing medications for patients has been debated and is now a clinical reality. The journey this change in practice has undertaken can be followed through the numerous publications around this topic.

So if there are so many good reasons to publish why do more HP's not do so? Unfortunately, although many health professionals are keen to publish this important activity is often not formalised as a part of our professional role and consequently, it has to be completed outside of normal professional activities. A way forward would be to encourage colleagues to discuss the possibility of writing for publication during their annual review with their employer so that the need for this activity can be recognised and time provided for it to take place within the individual's timetable.

Writing for publication is a different skill than writing, for example, an academic assignment. Therefore, the first stage in the process should be to find a mentor, someone who has successfully published and who can guide you through the process and provide critical feedback as the drafts of your potential paper emerge. Also writing, like any other activity, requires commitment and time and you will need to identify and safeguard some specific time to write your paper.

Educated tips for “novice” writers

The first “right” refers to the right topic. If there is a topic you are passionate about or have been involved in researching that you think would lend itself to publication you need to first conduct a review of the literature in this area to ascertain what has been published on this topic already. Second, you need to consider how the paper you are proposing to write will contribute to what is already known in this area or whether your work will add a different dimension to what is already known.

Make sure the topic you have chosen is as specific as possible. An error that many novice writers make is to try to cover too many aspects in one paper. Be clear about the aim of the paper, more does not mean better.

The second “right” refers to choosing the right journal. Different journals target different audiences and you need to consider whether the journal you are planning to submit your work to is aimed at an audience that would be interested in your work. The target audience for a journal can include researchers, clinicians, or managers.

To further complicate matters, there are generalist and specialist journals. If your paper has a strong rheumatological feel to it then a journal aimed at a rheumatology audience would be more appropriate than a non-specialist journal, the readership of which could not be expected to have the same knowledge base or indeed interest in such a specialist area. It is also worth bearing in mind whether a journal has a national or international audience. The creation of HP consultant roles has occurred in the UK but not across Europe or the United States of America. Consequently, a paper focusing on the evaluation of these roles may be considered to be only of national interest and this will influence the editor’s decision as to whether or not to accept such a paper.

It can be useful to send the editor an abstract of your proposed paper so that you can receive feedback at an early stage as to whether your paper would be relevant for the journal you have selected. Not all journals offer this facility but as editor of Musculoskeletal Care I certainly advocate this approach.

The 5 “rights”
The third "right" refers to right information. Each journal will have its own preferred way as to how the information should be presented. You need to obtain and follow the authors’ guidelines regarding the structure and content of the paper. All papers regardless of the topic should contain an introduction, the body of the manuscript (which in a research paper usually includes the methods, results, and discussion) and a conclusion.

Before writing, it is useful to obtain a copy of the journal you are planning to submit your work to so that you can familiarise yourself with the style of writing required and also to get a feel for how much information to include on different aspects of the paper. If you submit a paper that does not follow the authors’ guidelines then the paper will be returned to you and you will be asked to comply with the stated requirements, which only wastes time for both the publisher and yourself.

**Balance of content**

Common problems that occur during the preparation of a paper include an uneven balance of content (too much background and not enough in the other sections) and not providing enough information describing the methods used (the aim of the methods is that the reader should be able to replicate your study through the information you provide). Also it is easy for the novice writer to get muddled over what information to include in specific sections of the paper resulting for example in information that belongs in the methods section appearing with the results. This is why looking at papers that have already been published can guide you as to what information is appropriate to include in each section of your paper.

The fourth and fifth “rights” refers to the right words at the right time. Good grammar is essential and if this is not your strong point, then ask a colleague to read your work through and highlight any areas that need correction. Try and be concise in your writing. Also think about timing; is the message you are trying to convey, timely, and relevant? If you have conducted a piece of research many years ago and have procrastinated on this you may find that by the time you write it up the content is no longer relevant. A good reason not to put off your intention to publish your work.

Hopefully, I have convinced some of you to put pen to paper…

Sarah Ryan wants to remind health professionals that writing a scientific article is an art of its own. There is the first time for everything. She met Professor Sarah Hewlett (on the left) at the EULAR Congress in Paris.

To conclude, I will simply remind you of the 5 rights:

- topic
- journal
- information
- words
- time

Sarah Ryan
Nurse Consultant Rheumatology
Editor of Musculoskeletal Care

"The first stage should be to find a mentor, someone who has successfully published and who can guide you and provide critical feedback."

The main reasons why a paper is accepted are:

- the importance of the topic
- the timeliness of the topic
- authors guidelines have been followed
- research design is good
- well written
- pertinent to the aims of the journal

The main reasons why a paper is rejected are therefore the opposite of the above

- too wordy
- does not follow the authors’ guidelines
- reads like a paper written for a course
- poor research design
- the text is difficult to follow
- topic not pertinent to the journal
The next EULAR Congress will again be the venue of high-quality Scientific Sessions introducing health professional research and issues of interest in the practical health professional work. In 2010, there will be two abstract sessions. There will also be joint sessions organised together with rheumatologists and the Standing Committee of People with Arthritis/Rheumatism in Europe (PARE). The full programme is available at EULAR website.
Extended health professional roles

Extended roles can be defined as tasks which have not been commonly undertaken by health professionals or a certain group of health professionals to date, and which require at least additional training or education in addition to your basic professional training.

Planning the EULAR Congress 2011

The aim is to provide a forum of the highest standard for scientific, educational, and social exchange between professionals involved in rheumatology, liaising with patient organisations, in order to achieve progress in the clinical care of patients with rheumatic diseases.

Abstract submission for London 2011

The health professional abstract submission process is open until the 31st of January 2011. Health professionals can choose to submit their abstract either for practice and clinical care (topics A1 – A5) or for health professional research work (topics 7 – 27). For further information, see the EULAR website www.eular.org.

Health Professionals Travel Bursaries

Every year, EULAR awards a number of travel bursaries to the first or presenting author of a health professionals’ abstract that has been accepted for oral or poster presentation at the EULAR Annual Congress.

A travel bursary shall facilitate attendance at the EULAR Congress and includes:

• free registration (including one year free subscription to the ARD)
• a cash amount of 350 EUR for travel and living expenses
• three nights hotel accommodation (single use), booked by EULAR

All health professionals other than physicians are eligible. There is no age limit for these bursaries. The cash amount of the travel bursary will be paid in full on-site at the Congress only, and only to the eligible person. No prepayments will be made in any cases. Applications should be submitted via the electronic application system.


The EULAR Health Professionals Research Grant

Every year EULAR funds one health professional’s research project in the field of arthritis/rheumatism that is in line with the mission, objectives, and goals of EULAR. Projects will be funded up to a maximum of €30,000.

Recipients of a research grant must submit a mid-term report to the Scientific Sub-committee of the EULAR Health Professionals on the progress of the research project. After the completion of the project, the recipients must report the results to the EULAR Executive Committee. Furthermore, the recipients are expected to present their project in the EULAR HP newsletter and may be invited to present their findings at the Annual EULAR Congress.

Application process

Applicants must complete the official application form (including detailed budget), and include the full CV of the project leader as well as a project plan. For further instructions, see the official application form available at: www.eular.org/health_professionals_research_grants.cfm.

Applications for 2011 should be e-mailed to Ms. Caroline Pasche at the EULAR Secretariat (caroline.pasche@eular.org) so that they arrive by the 31st of December 2010. Applications will be evaluated by the Scientific Committee of the EULAR Health Professionals in early 2011. Applicants will be informed by e-mail.

The following evaluation criteria will apply:

• Scientific value
• Implementation and relevance for EULAR Health Professionals (i.e., how the project may improve the non-pharmacological management of patients in a short and/or long-term perspective, and/or whether the project may foster the development of a research network of relevance for the future beyond the period of the project)
• Quality of the work plan and methods
• Feasibility of the study within the planned timeframe
• Patient-centered approach (if applicable)
• Budget realistic for the planned project
• Planned dissemination and implementation of the research results

More information on the ongoing and finished projects supported with a research grant at: www.eular.org/research_supported_AHP.cfm.

Do you have good news for the newsletter?

Since 2000, the HP Newsletter has functioned as the main information channel of health professionals in rheumatology within EULAR. The newsletter is published twice a year featuring the work of health professionals and all aspects of multidisciplinary collaboration.

Please give us tips about health professional thesis, projects, and new research themes in the musculoskeletal field. Contact the editor of newsletter for further information at jaana.hirvonen@reumalitto.fi.
