

THURSDAY, 14 JUNE 2018

Patient involvement in research: The future of collaborative research. Lessons from the field of rheumatology and beyond

SP0058 PATIENT INVOLVEMENT IN RESPIRATORY RESEARCH

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The European Lung Foundation (ELF) mission is to bring together the public and patients with respiratory professionals to improve lung health. ELF was founded by and works in a unique partnership with the European Respiratory Society (ERS), a membership society for respiratory professionals. A core part of ELF's activities is to ensure that the perspectives of people living with a lung condition help to inform research, treatment and policy activities at a European level. ELF has extensive experience of facilitating patient engagement in research and clinical projects, including in EU-funded consortia, and has published extensively on the topic.

During this session, ELF will share its experience of involving patients in respiratory research collaborations. Focusing on three projects as exemplars of different stages of the research process, ELF will share some of the lessons, challenges, and key benefits of involving patients in research and will highlight how these can be transferred to projects beyond the respiratory field.

Research priority setting: the European Asthma Research and Innovation Partnership (EARIP) set out to develop a coordinated and integrated approach to the future of asthma research and development by creating a roadmap of the components needed to reduce the burden of asthma, in terms of the impact on individuals and on healthcare systems across Europe. ELF led a research priority setting process in which patient perspectives played a central role. The resulting research priorities have been taken forward by research funders and consortia, helping to ensure that the future research agenda is patient-centred.

Key lessons:

- how to involve patients in research priority setting
- how to build consensus between patient, clinical, research and industry stakeholders

Clinical trials:

the ground-breaking U-BIOPRED (Unbiased Biomarkers for the Prediction of Respiratory Disease Outcomes) project involved patients with severe asthma as equal partners. Up until this point, many projects funded by the EU Innovative Medicines Initiative (IMI) had limited or no involvement of patients. As a result of the successful partnership between patients and professionals, IMI asked the project to develop a guide to patient involvement in EU-funded research so that the experience could be transferred to other disease areas. U-BIOPRED is still considered a pioneering project in terms of its level of patient involvement and many new studies use the approach as the exemplar for how to engage patients as partners.

Key lessons:

- how to involve patients as equal partners in clinical research
- how to maximise the opportunities for patient input
- where patients can add value to clinical projects

Disease registries:

the European Multicentre Bronchiectasis Audit and Research Collaboration (EMBARC) is an ERS Clinical Research Collaboration dedicated to improving research and clinical care for people with bronchiectasis. EMBARC has created a European Bronchiectasis Registry, funded by the ERS and by the EU IMI Programme. Patients have played a central role in defining the scope, ethics, governance and data protection processes for the registry and the next phase of the project will include a patient-powered registry in order to capture patient-important outcomes directly from people affected by bronchiectasis.

Key lessons:

- patients' and clinicians' recommendations for involvement in research – dos and don'ts
- how to involve patients from rare disease communities in research

Conclusion: Patient involvement in respiratory research has grown significantly over the last decade. Patient perspectives are increasingly considered to be a core component of every research project and the wider respiratory community values the important role patients now play. ELF has facilitated the involvement of people with lung conditions in a wide range of research projects and the lessons learned are highly transferable to other disease areas and settings.

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SP0059 EULAR'S PATIENT RESEARCH PARTNER NETWORK – PATIENTS' FUTURE INVOLVEMENT IN RESEARCH

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Research in the field of RMDs, particularly in Europe, has advanced significantly the last years. In particular, **the interest in developing Patient Reported Outcomes (PROs) and forms of participatory research has grown**. In the field of rheumatology there have been undertaken many initiatives to explore and implement participatory research.

Substantial unmet needs in the area of research, highlighted in the **RheumaMap** (developed by EULAR), will however require an altogether **higher level of commitment and innovation**. Implementation of the distinct elements contained in RheumaMap will rely on scientists, patients and health professionals.

In this regard EULAR PARE has developed **recommendations for patient-researcher collaboration** and also established a network of **40 trained patient research partners** of whom 6 have also graduated for the EUPATI training course.

Last year it was created a **platform** (under the name of **Study Group for Participatory Research**) for knowledge exchange regarding patient participation in rheumatology care and research with the aim of establishing a group of researchers and patient research partners with an interest in developing innovative methods to elicit the voice of patients in rheumatology research, to stimulate the dialogue about the rationale, principles and conditions for patient involvement in research and to discuss and develop the nomenclature and methodology of evaluating the process, results and impact of patient participation in research and health care innovation.

The Learning Objectives of the session are as follows:

- To learn from best practices of patient engagement in different disease areas
- To explore patient involvement in guideline development and health care innovations
- To explore how to evaluate patient involvement
- To explore how to cease the moment, how to have fun in the process

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EULAR Projects in musculoskeletal imaging

SP0060

EULAR RECOMMENDATIONS FOR THE USE OF IMAGING IN MECHANICAL LOW BACK PAIN

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Background: Low back pain is common and relates to a variety of overlapping pathologies. Imaging of the spine has a high priority in the assessment of patients with low back pain. However, studies have shown that clinicians vary widely in how frequently they obtain imaging tests for assessment of low back pain. Technical advances in the field of lumbar spine imaging are made at an increasingly high rate, and it seems likely that improved imaging procedures can indeed increase the understanding of low back pain and aid the diagnostic precision to the diagnostics of mechanical low back pain. The EULAR Task Force consists of radiologists, orthopaedic surgeons, rheumatologists, doctors in physical medicine and general medicine, physiotherapist and patients and the aim of the group was to develop evidence-based recommendations for the use of imaging modalities in low back pain with or without radiculopathy

Based on PICOs established at the first meeting and using European League Against Rheumatism (EULAR) standardised operating procedures a systematic literature review was conducted to retrieve data on the role of imaging modalities including both conventional, contrast enhanced and dynamic approaches in radiography, ultrasound, MRI and CT. The recommendations will be based on the results of the systematic literature review and expert opinion and will be relevant for to all health care professionals who treat mechanical low back patients due to its multifactorial nature.

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MRI

SP0061

HOW TO USE MRI IN THE DIAGNOSIS AND MANAGEMENT OF PSORIATIC ARTHRITIS + CLINICAL CASES

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Psoriatic arthritis (PsA) is an inflammatory joint disease characterised by presence of arthritis, enthesitis and/or spondylitis in patients with psoriasis. PsA presents a wide range of disease manifestations in various patterns. Imaging is an important part of management of PsA and is used for multiple reasons including establishing/confirming a diagnosis of inflammatory joint disease, determining the extent of disease, monitoring activity and damage, assessing therapeutic

efficacy, and identifying complications of disease or treatment, in the setting of clinical practice or clinical studies.

Magnetic resonance imaging (MRI) allows detailed assessment of all peripheral and axial joints and entheses involved in PsA and can visualise both inflammation and structural changes. This talk will provide an overview of the status and perspectives of MRI in diagnosis and management peripheral and axial PsA.

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SP0062

HOW TO USE MRI IN THE DIAGNOSIS AND MANAGEMENT OF OSTEOARTHRITIS

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The recent EULAR recommendations for the use of imaging in the clinical management of peripheral joint osteoarthritis (OA) provide an excellent, evidence-based, multi-disciplinary way background to this topic.

For diagnosis, the importance of a detailed history and thorough examination can never be underrated. Imaging should be used as only part of the diagnostic criteria for any rheumatic disease. One of the key EULAR recommendations is that imaging is often not required to make the diagnosis when patients present with a typical presentation of OA, with short-duration morning stiffness and increasing pain with prolonged weight bearing. The major benefit for imaging is in helping differential diagnosis in atypical presentations, and generally radiographs (weight-bearing for the knee) would be used first.

MRI brings its unique 3D strengths to diagnosis. MRI may play a role in the diagnosis of a meniscal tear, but this should only be considered where there is a clear history of locking or blocking to joint extension, rather than gelling (after prolonged immobility) or 'giving way', the latter being usually a sign of muscle weakness. When using MRI it is useful to remember that some degree of synovitis is common in osteoarthritis, and the presence of effusion or synovial hypertrophy does not automatically mean a primary inflammatory arthritis. Another common imaging feature is the bone marrow lesion (BML). This has similar juxta articular location in OA and rheumatoid arthritis, though the pathology is markedly different: BMLs represent osteitis in rheumatoid arthritis but areas of micro-fracture, necrosis and fibrosis in osteoarthritis. So clinical context is critical.

Routine imaging for OA follow up is usually not required unless there is an unexpected rapid progression of symptoms in which case a number of diagnoses should be considered. BMLs show areas of osteonecrosis, so a biopsy report suggesting this is should not be confused with avascular necrosis (AVN). AVN is a condition resulting from the disruption from the vascular supply to a particular bone, often the femoral head, leading to resorption of subchondral trabeculae and clinically related to prolonged corticosteroid use, alcohol excess or previous surgery. It's also been seen in connective tissue diseases. Patients may be under the age of 50, unlike the average age of rapidly progressive osteoarthritis (RPOA). RPOA is relatively uncommon and figures on its incidence vary widely. It is most commonly described again in the hip joint, and it may be the result of secondary osteonecrosis after subchondral fracture. This lesion is of importance because increased frequency of RPOA has been seen in trials of the anti-nerve growth factor monoclonal antibodies in the last decade, where there may be a link to concomitant NSAID use. Subchondral insufficiency fractures (SIF) are another cause of sudden onset pain, usually in the medial side of the knee and not associated with a previous history of trauma. There is a high prevalence of related meniscal tears. This tends to be seen in older females and is associated with the subchondral crescent sign indicating a fracture.

In terms of guiding treatment, at present we do not have evidence that the presence of particular pathologies such as BMLs or synovitis should indicate targeted therapies for those pathologies, though (appropriately) a lot of research is currently underway to see if these do represent legitimate targets for existing and novel therapies.

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