SP0054 THE CONTRIBUTION OF REGULATORY B CELLS IN PROTECTING RHEUMATIC DISEASES

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B cells are considered central to the pathogenesis of patients with rheumatic diseases (RD) including Systemic lupus erythematosus (SLE) and rheumatoid arthritis (RA). In addition to producing autoantibodies, B cells suppressing inflammatory responses, known as regulatory B cells (Bregs) are numerically and functionally defective in rheumatic diseases. The production of interleukin 10 (IL-10) classically defines a Breg, however the stability and/or plasticity of this population is not well understood. In addition to producing autoantibodies, B cells suppressing inflammatory responses, known as regulatory B cells (Bregs) are numerically and functionally defective in RD patients. The production of interleukin 10 (IL-10) classically defines a Breg, however the stability and/or plasticity of this population is not well understood. Additionally, IL-10 +B cells have been shown to co-express pro-inflammatory cytokines such as TNF α and IL-6, further complicating Breg classification. Characterising the signals inducing Breg differentiation and the subsequent stability and/or plasticity of this population may aid in understanding the factors contributing to Breg dysfunction in RD patients. Novel findings unravelling the signals required and the stability of Bregs versus B effector cells in RDs will be discussed.

Disclosure of Interest: None declared

DOI: 10.1136/annrheumdis-2018-eular.7731

THURSDAY, 14 JUNE 2018

Sustainable healthcare in rheumatology and the role of health professionals

SP0055 HOW CAN INTEGRATED HEALTHCARE CONTRIBUTE TO SUSTAINABLE HEALTHCARE IN RHEUMATOLOGY?

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Introduction: According to the World Health Organisation (WHO) "an integrated, people-centred approach is crucial to the development of health systems that can respond to emerging and varied health challenges, including urbanisation, the global tendency towards unhealthy lifestyles, ageing populations, the dual disease burden of communicable and non-communicable diseases, multi-morbidities, rising health care costs, disease outbreaks and other health-care crises". In supporting health services to become more integrated and people-centred a Framework was developed that proposes five interdependent strategies: 1. Empowering and engaging people and communities; 2. Strengthening governance and accountability; 3. Reorienting the model of care; 4. Coordinating services within and across sectors; 5. Creating an enabling environment. Given that health systems are highly context-specific, the Framework does not propose a single model but interdependent (sub) strategies, policy options, and interventions that need to be adopted.¹ What is known about the adoption of these strategies for people with rheumatic and musculoskeletal diseases?

Methods: A convenience sample of recently published reports about redesigning health care for people with rheumatic and musculoskeletal diseases is assessed against the WHO Framework on integrated-people centred health services. The five interdependent strategies, including the policy options and interventions as defined under the Framework, are assessed for presence, implementation fidelity and outcomes. Implementation fidelity refers to the degree to which an intervention is delivered as intended (i.e. in line with the Framework). Outcomes of people-centred care include: equity in access, quality, responsiveness and participation, efficiency, and resilience.

Results: To be presented at the conference.

Discussion: It is anticipated to find a plethora of examples of mainly single policy options and interventions, but hardly any examples of combinations of strategies. This would indicate a need for a systems approach in achieving sustainable healthcare in rheumatology.

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Disclosure of Interest: None declared

DOI: 10.1136/annrheumdis-2018-eular.7841

SP0056 SUSTAINABLE HEALTHCARE – IT TAKES A VILLAGE

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Healthcare delivery is at a crossroads for potential paradigm change due to budget constraints, complexity of care, increasing performance measures and implementation of electronic health records. Additionally, recent reports of high levels of stress and burnout amongst healthcare providers has been linked to decreased patient safety and medical errors. Complicating matters for rheumatology, is shrinking of the available workforce. The model of interprofessional healthcare delivery holds promise as a means to improve both patient outcomes and provider wellbeing. This presentation addresses implementation of interprofessional teams in rheumatology and provides a review of successful models and guidelines for implementation.

Disclosure of Interest: None declared

DOI: 10.1136/annrheumdis-2018-eular.7718

THURSDAY, 14 JUNE 2018

SSc: From registries to trials – do we have sufficient data and the appropriate design?

SP0057 THE COURSE OF SYSTEMIC SCLEROSIS (SSC): WHAT CAN WE LEARN FROM REGISTRIES?

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SSc is a heterogeneous connective tissue disease with an unpredictable course and a high mortality and morbidity. Although the identification of patients in early stages of disease is increasingly achievable thanks to the introduction of the new ACR/^{EULAR 2013} classification criteria, the stratification of patients according to the risk of disease progression or of severity of disease is still an unmet need. Several potential predictive factors of disease evolution have been proposed over the years: SSc specific autoantibodies related to disease complications, serum biomarkers of internal organ involvement, age at diagnosis, sex, disease subset seem to have a prognostic value but unfortunately all these may be present in different combinations making it difficult to identify how the disease will evolve. Data from registries of different countries confirm that the clinical presentation depends on several factors. Data from EUSTAR group data base indicate that a late age at onset (>75 years) of SSc is associated with more aggressive disease as well as the male gender, that has a more severe phenotype and a worst prognosis than female, with an increased risk of occurrence of cardiovascular involvement. The analysis of geographic variations among different SSc presentations may suggest that eastern centres care for more severe SSc manifestations in Europe. Data from EUSTAR group reported also that the main causes of deaths in SSc are due to pulmonary fibrosis, pulmonary arterial hypertension (PAH) and heart involvement (mainly heart failure and arrhythmias). Independent risk factors for mortality and their seem to be proteinuria, the presence of PAH based on echocardiography, pulmonary, forced vital capacity below 80% of normal, dyspnoea above NYHA class II, reduction of dlc, patient age at onset of Raynaud's phenomenon and the modified Rodnan skin score. Interestingly, SSc patients show an increase risk of lung cancer (especially non small cell lung carcinoma) in association with interstitial lung disease and of esophageal or cardiac adenocarcinoma. Data from the database of the German Network for Systemic Scleroderma support the concept that SSc-overlap syndromes should be regarded as a separate SSc subset, distinct from lcSSc and dcSSc, due to a different progression of the disease, that had an intermediate rate of disease progression in between lcSSc and dcSSc, different proportional distribution of specific autoantibodies, and of different organ involvement. Therefore, the use of registries is today of paramount importance to obtain significant data about several unmet needs in SSc.

Disclosure of Interest: None declared

DOI: 10.1136/annrheumdis-2018-eular.7871

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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Disclosure of Interest: None declared

DOI: 10.1136/annrhumdis-2018-eular.7746

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

Disclosure of Interest: None declared

DOI: 10.1136/annrhumdis-2018-eular.7785