How to perform low-budget high-quality research

SP0016 YOUR VERY FIRST STEPS ON SYSTEMATIC REVIEW
Loreto Carmona, Instituto de Salud Musculosquelética, Research, Madrid, Spain

Systematic reviews (SR) are a type of clinical research, and thus they follow the hypothetico-deductive or scientific method. Their objective is to answer clinical questions and they do it based on a specific structure (protocol) and working through inferences. Interestingly, a SR is a type of study design that can answer all types of questions, from efficacy to incidence. They manage the information from previous studies in a pre-established reproducible way, as unbiased as possible. They provide quick answers. However, they should be performed and interpreted with caution: a poor systematic review is much worse than a narrative review, as it gives the false impression of “science”. This is even worse if the studies were combined in a meta-analysis.

In this lecture, we will review the protocol of a SR, the importance of rephrasing the question, the search strategy, selection criteria, and procedures of studies selection, primary endpoints, and quality and risk of bias. The last part of any SR is the analysis, which is always qualitative, supported by the evidence table, and sometimes quantitative (meta-analysis). We will review some methods to evaluate publication bias, to combine results, and to explore heterogeneity. In this sense, it is essential to note that if we cannot find a valid explanation for heterogeneity, our results may not be valid.

Disclosure of Interests: Loreto Carmona Grant/research support from: Abbvie, Actelion, Astellas, BMS, Eisai, Gebro Pharma, Grünenthal, Leo Pharma, Lilly, MSD, Novartis, Pfizer, Roche, Sanofi-Aventis and UCB Pharma, Paid instructor for: Novartis

SP0017 USING AVAILABLE DATASETS TO ANSWER NEW RESEARCH QUESTIONS
Daniel Prieto-Alhambra, University of Oxford, NDORMS, Oxford, United Kingdom

Background: Clinical data are continuously recorded in clinical encounters in the form of electronic medical records, registries, audits ans similar databases. Such large datasets are available to researchers, and provide unique opportunities. However, challenges arise from the use of routinely collected data, that need special attention and specific skills to minimise a waste in research.

Objectives: To discuss available data sources (data discovery), their advantages and limitations, their uses, and to cover examples of research conducted using routinely collected datasets.

Methods: We will discuss a list of data sources at high level (types of data), their main pros and cons, and then cover challenges and solutions through a number of previously published examples.

Disclosure of Interests: Daniel Prieto-Alhambra Grant/research support from: Grants from Amgen, UCB Biopharma and Servier outside the submitted work, Consultant for: UCB Biopharma, Speakers bureau: Amgen

Health Professional Welcome session

SP0018 WHAT YOU SHOULDN’T MISS FROM THE HPR PROGRAMME AS A CLINICIAN
Maria Bergström, Linköping University, Department of Social and Welfare Studies, Division of Occupational Therapy, Norrköping, Sweden

As a health professional, the EULAR congress is the place where I can get access to new and fresh rheumatology research of good quality. My presentation will take you through the possibilities the congress offers clinicians when it comes to different topics within the area of rheumatology. Further, my aim and hope is to give you a sense of what is in store for you during this year’s EULAR congress. People with rheumatic diseases today live their lives to a great extent having the diagnosis affecting their everyday life. The ability to work, interact with others or engaging in activities they want to, can be limited. So what do we need to know about them in order to provide the best possible treatment and rehabilitation? As a health professional clinician, I look forward to finding some of the answers to this during this congress.

During the EULAR congress, we as health professionals have the possibility to contribute to and acquire research of good quality in rheumatology, on our way to give our patients the best possible treatment. Also, we have the possibility to contribute to the patients’ health, and I look forward to sessions touching health topics such as exercise. The quality of research and the variety of topics during this EULAR congress can give us a bigger set of tools to work with when we get back to our patients and continue our path towards the best possible treatment and health for this big and important group of patients. I hope that this session can provide an overview of what this year’s congress can offer from a clinical perspective.

Disclosure of Interests: None declared

EULAR Projects in paediatric rheumatology

SP0019 PRES HPR: DONT DELAY, COLLABORATE TODAY
Jeanette Cappon1, PReS Committee for Health Professionals1, Department pediatric rehabilitation, Reade Center for rehabilitation and rheumatology2, Dutch Health Professionals in Pediatric Rheumatology3, Reade Center for Rehabilitation and Rheumatology, Pediatric Rehabilitation, 1056AB Amsterdam, Netherlands

Background: The Pediatric Rheumatology European Society (PReS) is an international organization based in Europe which is dedicated to advance the care and improve the health and well-being of children and young people with rheumatic conditions, helping them to reach their full potential. Full PReS membership is extended to individuals from all European countries, whether they are within the EU or not, and includes countries in the middle east and from other parts of the world as associate members to enrich the collective experience and knowledge. PReS welcomes every practitioner/researcher in the field of pediatric rheumatology.

The PReS committee for Health Professionals in Pediatric Rheumatology aims to bring together nurses, physical therapists, occupational therapists, social workers, psychologists, podiatrists and other health professionals (HP) to foster dialogue, to set standards of clinical practice, education and research. Collaboration between PReS and Eular Health Professionals starts today, here in Madrid.

Collaboration in general starts with a shared goal to work on together. Our young patients of today might be your patients of tomorrow: what should you know about what they have been through? Your patients of today might have been our young patients of yesterday: what can we learn from their experiences of the past being a child with a rheumatic condition? Did they receive comprehensive care that sustained into their adulthood?

Objectives: To find shared goals between HP Eular and HP PReS to deliver comprehensive care for people with rheumatic diseases during their full life. To find common interests to discuss between HP Eular and HP PReS

Methods: Examples of common interests e.g. supporting self management of pain and health and illness education are presented.

Results: Health Professionals from Eular and PReS experience common interests and shared goals. Positive relations are expected to develop upcoming years.

Conclusion: CollaboRelation between HP Eular and HP PReS can start today

Disclosure of Interests: None declared
outcomes may be worse and that children in these countries face the additional burdens of poverty, socio-political instability and communicable diseases.14 Objectives: To review the current situation and challenges faced by the children in less resourced countries with rheumatic diseases and those who provide medical care for them, and to explore opportunities that will drive the global development of paediatric rheumatology to the benefit of all children with rheumatic diseases.

Methods: A thorough review of published literature and gaps in knowledge on the epidemiology and outcomes of childhood rheumatic diseases from less resourced countries. A review of current and planned global initiatives to improve Paediatric Rheumatology care in less resourced countries.

Results: Despite increasing emerging data on paediatric rheumatic diseases from less resourced countries, data on paediatric rheumatic diseases from less resourced countries are sparse. Paediatric rheumatology services in most countries remain inadequate or non-existent to serve the needs of the population, despite encouraging growth in some areas. Improvements in healthcare systems in these countries offer opportunities for the growth of paediatric rheumatology care. Greater genetic diversity and different disease profiles offer opportunities for the advancement of genetic and environmental influences on rheumatic diseases.

Conclusion: An organised effort from the paediatric rheumatology global community can play an important role in the development of education, networks, services and research capabilities that could lead to increased scientific growth and clinical benefits for all children with rheumatic diseases, regardless of their geographical or socio-economic position.

REFERENCES:

Disclosure of Interests: None declared

SP0022 PROJECT ABSTRACT 2: EMERGE – HELPING DELIVER OUR WORLDWIDE GOALS

Nicolino Ruperto, Istituto Gaslini, Clinica Pediatrica e Rheumatologia-PRINTO, Genoa, Italy

The treatment of pediatric rheumatic diseases has improved tremendously in the last 20 years thanks to appropriate legislative initiatives, the existence of very large collaborative networks and the availability of new potent medications. In particular there has been a tremendous improvement in a sizable proportion of patients with juvenile idiopathic arthritis (JIA) with over 3500 children enrolled in trials with registries of recent years. For JIA now the tendency is to concentrate on oral therapies and on drugs targeting specific JIA categories. Also in juvenile systemic lupus erythematosus (SLE) the childhood counterpart of SLE there are several potential targets to be tested in children. In addition the field of paediatric rheumatology has provided an excellent example of large scale academic studies which, through the Paediatric Rheumatology International Trials Organisation (PRINTO) have enrolled over 38,000 children from over 60 countries.

Further improvement in future years will stem from a better definition of the paediatric disease entities, the discovery of laboratory and imaging biomarkers that could help the tuning of therapy, a smoother implementation of clinical trials, a more standardized link between academia (clinical and basic science), regulatory authorities, learned societies such as the Pediatric Rheumatology European Society (PReS) and family organisations for the planning of future trials.

This lecture will present a general overview and a perspective for the future (mainly academic) work to align clinical data collection with basic researchers, PRES, and family associations in order to foster and facilitate drug evaluation in pediatric rheumatic diseases as well as academic research.

REFERENCES:

EMERGE (EMerging Rheumatologist andf researchers) is a new group of young physicians and scientists from across the globe with a shared interest and passion for pediatric rheumatology. Amid numerous differences in education, research opportunities and healthcare systems across countries, the overarching aim of the group is to work closely together towards the same goal of providing a better possible care for children with rheumatic diseases. With the support of the Pediatric Rheumatology European Society (PReS), the group has created several compelling initiatives which could help the creation of a new generation of professionals who can deliver this goal. Therefore, one of the paramount initiative of the group is the PReS EMERGE fellowship. This unique program enables clinicians and scientist from all over the world to come to the established pediatric rheumatology centers in Europe, receive clinical or translational research training, perform a short study and build a support network readily available after returning to their surroundings. Next, the Peer Review Mentoring Program has been recently started in order to provide a first structured peer review training in the field of pediatric rheumatology. The prevailing intention of this initiative is to improve the quality of published researches by education of the future peer reviewers. The important initiative of the group is also the organization of the Young Investigators Meeting (YIM), that takes place every year before the PReS congress. This meeting gathers many clinicians and scientist from all continents and provides them with an excellent opportunity of presenting their basic and clinical discoveries and compelling cases to their peers and “not so senior” faculty. Besides, the group is involved in the organization of many educational courses where world-leading experts are conveying their experience and knowledge of a particular topic. To succeed in these initiatives, the EMERGE group is working closely with other similar groups, such as CARRA young investigators from North America and EMEUNET group of young adult rheumatologist from Europe. Moreover, the group has a firm collaboration with Pediatric Task Force Global Musculoskeletal Health, a group dedicated to raising the awareness and improving access to right care for children with musculoskeletal diseases, and ENCA, a network of national associations working with children and young people with pediatric rheumatic diseases. Finally, in order to spread information about these initiatives and to attract new members, the group is actively using social media platforms, such as Facebook (https://www.facebook.com/PReSEMERGE/), Twitter (@PReSEMERGE), and bi-monthly newsletters (emerge.pres@gmail.com).