# EULAR Standing Committee of Epidemiology and Health Services Research (ESCEHSR) Business Meeting

# Madrid, 13th of June 2019

#### Please refer to slides for additional details

Chair: Laure Gossec (rapporteur)

Chair-elect: Pedro Machado

Participants: 49 participants from 16 countries.

## 1. Welcome and introductions; news from the EULAR Executive Committee

The incoming chair is Pedro Machado and introduces himself.

News are shared regarding the EULAR congress: the Congress this year is expected to have ~14000 participants coming from 130 countries and nearly 5000 abstract submissions, 45% of which accepted for presentation (350 oral presentations and 2200 posters). Spain (n=494), Italy (n=400) and USA (n=363) were the top three countries submitting abstracts.

Elections took place on Wednesday, 12<sup>th</sup> of June 2019. The new President-Elect is Professor Annamaria Iagnocco, from Italy, and the new Treasurer is Professor Daniel Aletaha, from Austria.

A discussion will take place at the Executive Committee level about the possibility of restructuring the EULAR Executive and Standing Committees and the way funding decisions are taken (aiming for better integration with the EULAR strategy).

A reminder about the EULAR 2023 strategy was provided.

The idea of a EULAR virtual research centre was presented. The strategy of EULAR proposes that by 2023 it will have established a European centre for RMD research to advance high quality collaborative research. This strategy is motivated by the fact that EULAR defines important benchmarks and recommendations for rheumatology. But research remains fragmented and to make an impact at the level of the EU and beyond will require concerted effort. A suitable form of framework for the required research effort is needed and EULAR is working on framework.

An overview of EULAR advocacy initiatives was provided, including EULAR Public Affairs Group, WAD conference 2018/position paper, EU Parliament Interest Group on Rheumatic and Musculoskeletal Diseases, and World health Organisation (WHO) and RMDs.

An update about the EULAR journals was provided: ARD and RMD Open.

An update about FOREUM and the next expected funding calls was provided: "gender differences in RMDs" and "rising stars fellowship/grant".

Any ideas or suggestions regarding the future structure and functioning of the EULAR Standing Committees will be greatly appreciated and should be sent to Pedro Machado/Laure Gossec.

## 2. Report from the EULAR 2020 Scientific Committee Meeting

The Scientific Chair will be Professor John Isaacs; the Abstract Chair will be Professor Loreto Carmona, one of the previous ESCEHSR chairs.

There are three abstract topics that are particularly relevant for the ESCEHSR: 1) Public health, health services research, and health economics; 2) Epidemiology, risk factors for disease or disease progression; 3) Validation of outcome measures and biomarkers.

The ESCEHSR chair will try to populate the Congress with sessions/presentations that are relevant to our standing committee but a specific "track" does not exist. Suggestions for presentations/sessions are welcome. Ideally, suggestions should include: 1) Session title and objectives, 2) Title of 1st presentation and speaker; 3) Title of 2nd presentation and speaker. Ad hoc suggestions for presentations are also welcome. Please send suggestions to Pedro Machado by the end of August.

## 3. SCEHSR study groups

ESCEHSR has currently 2 active study groups; both have put up posters presenting their activities at this congress. These study groups are open and welcome interested people to join. New study group proposals are also welcome; study groups could be a good starting point for the development of EULAR task forces.

- a) The "Public Health of RMDs and Health Services Research" study group: the leader is Suzanne Verstappen (UK). The group has an active project around the evidence for prevention of RMDs.
- b) The "Epidemiology" study group: the leader is Axel Finckh (Switzerland). Related task forces are the "Big Data and Digital Health" task force, led by Laure Gossec (article published in ARD) and the "Points to consider when analysing and reporting comparative effectiveness" task force, led by Delphine Courvoisier and Axel Finckh (first meeting took place in March 2019).

#### 4. Update on Courses

- a) The EULAR course on health economics in rheumatology is organized by Francis Guillemin and Bruno Fautrel (both France). The second edition of this course took place 5-6 April 2018, 21 participants, very high satisfaction (mean 9.4/10), on budget, next course is planned for 26-27 March 2020.
- b) The EULAR Epidemiology Course is organized by Laure Gossec (France) and Pedro Machado (UK). The 6th edition (Theme: Outcome Measures) took place 29-30 June 2018, 29 participants, very high satisfaction (mean, 9.4/10), on budget, next course planned for 26-27 June 2020.
- c) <u>The EULAR Registers and Observational Drug Studies</u> meeting/course focuses on observational longitudinal data sets and many issues around registries. The third

version of this course (now organized by Loreto Carmona (Spain) & Elena Nikiphorou (UK)) is planned for 18-19 October 2019, in Amsterdam, the Netherlands.

## 5. Ongoing projects within or associated with ESCEHSR (please see slides)

- a) EULAR points to consider for Big Data (Laure Gossec, Tim Radstake): project accepted in 2018, meeting in Feb 2020, paper published in ARD recently.
- b) EULAR Outcome Measures Library (Loreto Carmona, also on behalf of Laure Gossec and Isabel Castrejon): this is a repository of outcome measures in many languages. The website is live since 2012, includes 169 outcome measures and is now available in the EULAR app. Loreto reiterated that she would be happy to pass this along to someone else Sofia Ramiro (Netherlands) kindly agrees to coordinate the OML.
- c) Development of recommendations for a core data set for pregnancy registers in rheumatology (Anja Strangfeld, Rebecca Fischer-Betz, Angela Zink) - Manuscript in preparation, oral presentation at EULAR 2019.
- d) EULAR Points to consider for lifestyle behaviour to prevent progression of RMDs (Suzan Verstappen, Francis Guillemin) ongoing, project accepted in 2018.
- e) EULAR points to consider when analysing and reporting comparative effectiveness research with observational data in rheumatology (Delphine Courvoisier, Axel Finckh) ongoing, project accepted in 2018.
- f) EULAR Points to consider when designing, analysing and reporting studies with work participation as outcome among patients with inflammatory arthritis (Annelies Boonen) ongoing, project accepted in 2018.
- g) EULAR standardised operating procedures for implementing recommendations (Estibaliz Loza, Loreto Carmona) ongoing, project accepted in 2019.
- h) EULAR Task Force to establish the evidence base and need for a EULAR Women's Network for Clinical Academics (Laura Coates, Laure Gossec) - ongoing, project accepted in 2019.

#### 6. AOB

We close the meeting and thank Laure for her work as Chair. She will continue as Past-Chair of ESCEHSR.