

EULAR Epidemiology and Health Services Research (ESCEHSR) Business meeting

EULAR 2018, June 15, 2018

Chair Laure Gossec (rapporteur), chair-elect Pedro Machado

Participants : 32 persons from 17 countries.

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

The Chair Elect is Pedro Machado and introduces himself.

News are shared regarding the EULAR congress: The Congress this year is expected to have ~14000 participants and nearly 5000 abstract submissions (a record). Several abstract sessions feature epidemiology and outcomes research.

2. EULAR strategy and funding for projects from EULAR

The EULAR strategy has been updated (please see slides). Here is the full version of the 6 strategic objectives:

1. ESOR: By 2023, EULAR will be the leading provider of education in rheumatic and musculoskeletal diseases (RMDs).
2. Congress: By 2023, EULAR will provide the foremost RMD congress experience, building on the heritage of our outstanding annual meeting.
3. QOC: By 2023, EULAR will deliver pre-eminent comprehensive quality of care (QOC) frameworks for the management of people with RMDs.
4. Research: By 2023, EULAR will have established a European centre for RMD research to advance high quality collaborative research.
5. Advocacy: By 2023, EULAR's activities and related advocacy will have increased participation in work by people with RMDs.
6. Governance, Infrastructure, Financials: By 2023, EULAR will have established governance, workflows and infrastructure to deliver the EULAR strategic objectives.

Objective 3 on Quality of Care includes the following elements:

Comprehensive quality of care (QOC) framework:

1. Recommendations / Best practice guidelines
2. Tools helping better implementation of guidelines into daily practice
3. Provide best practice across countries
4. Outcome measurement advice (Outcome measures & benefit evidence for users)
5. Define Roles & Responsibilities (Roles and responsibilities along the patient journey)
+ Competencies needed for HPRs

6. Education

7. Registries

Now we are at the implementation phase. EULAR has a budget to help with this implementation. This will be the priority now which means that projects which do not fall within these objectives will probably not be funded.

J. Bijlsma has announced EULAR plans to dedicate around one million EUR per year to support the project ideas that are approved and accordant to the new strategic goals. In addition, a project manager will be assigned to help ensure that the project process are well administrated, documented and timely implemented.

In September 2018, all StCs & EMEUNET will be expected to propose all their (even preliminary) ideas for projects to be submitted already or for the EC meeting for March 2019. Ideas will be open for the EC to challenge, comment and a final decision will be given for execution or review.

Laure asks the participants to think of project ideas (some ideas proposed by Laure are on the slides but are only indicative!) and link them to a strategic objective (objective 3 is the most logical for ESCEHSR).

The suggestion made today is to propose practical projects and to prepare a EULAR standard proposal or even a shorter one pager this Summer. Indeed, the next EULAR Exec meeting is in September so time is short! **Please prepare a word document including aim, methods, Convenor and budget if possible** (Laure proposes to aim for 50k-100k euros). Please look at the eular format for projects!

Please send such proposals to Laure (as Chair of ESCEHSRi) ideally before July 15...and before Sep 1 at the latest so that they can be sent to EULAR by Sep 10 which is the absolute limit.

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.

- A. The Public Health of RMDs and Health Services Research study group: the leader is Suzanne Verstappen (UK). The group is currently starting a project which was accepted this month by EULAR, around the evidence for prevention of RMDs.
- B. The Registers study group: the leader is Axel Finckh (Switzerland).

The group has met at this congress. 2 ideas where discussed and should be submitted to EULAR for September:

- *Legal issues with sharing data within the new EU data protection act. (Anna Molto)*

- *Points to consider when reporting effectiveness in observational settings and reporting response rates. The current situation for (Delphine Courvoisier).*

If you are interested in areas related to these study groups please contact the group leaders! All the study group leaders would welcome new study group members - please feel free to contact the leader if interested.

Also, proposals for new study groups are welcomed.

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 version of this course took place in April 2018. There were more than 30 applicants this year and the course was very much appreciated.
- B- The EULAR Epidemiology Course will run for the 6th time, on 29-30 June 2018, in Berlin Germany., The course is organized by L Gossec and Pedro Machado (UK). This year, similarly to last year, the course focuses on 'Outcome Measures'.
- C- The EULAR Registers and Observational Drug Studies meeting centres 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 proposed for November 2018 – look out for the application process when it opens!

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

- A. 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 154 outcome measures and is now available in the EULAR app. Loreto would be happy to pass this along to someone else – please contact her if you are interested!
- B. Workforce requirement study: finished and ready for submission (C. Dejaco).
- C. Core Data Set for GCA: finished, manuscript ongoing (F. Buttgerit).
- D. Health lifestyle in RMDs: approved by EULAR EC, will start this year (S Verstappen).
- E. Laure presents a Roadmap for Big Data project - EULAR Roadmap for Big Data and e-health in rheumatology- which will be submitted to EULAR for September (please see slides).

AOB

Concerns are expressed about the use of a tracking device by EULAR - concerns if this could be linked to the individual and data protection issues. This is brought back to EULAR Exec by Laure.

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| We close the meeting and thank the Past Chair Axel Finckh for all his work! |
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