Minutes of the EULAR Standing Committee on Epidemiology and Health Services Research (SCEHSR) Business meeting

**Date and place:** June 17, 2010; room 7J Fiera di Roma Congress Center, Rome

**Present:** Angela Zink (Chair), Jaime Branco (Portugal), Raquel Lucas (Portugal), Monika Mustak (Austria), Bruno Fautrel (France), Francis Guillemin (France), Laure Gossec (France), Helgi Jonsson (Iceland), Koray Tascilar (Turkey), Necati Cakir (Turkey), Estibaliz Loza (Spain), Sebnem Ataman (Turkey), Luc de Clercq (Belgium), Oili Kaipiainen-Seppänen (Finland), Rafic Baddura (Lebanon), Loreto Carmona (Spain, future chair), Martin Neovius (Sweden), and Marie Holmqvist (Sweden).

**Chair Report on meetings of the Executive Committee (ExCo) and the SC chairmen relevant to the SCEHSR held on June 14th**

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<td>Iain McInnes</td>
<td>Daniel Aletaha</td>
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<td>Imaging</td>
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<td>Mikkel Ostergaard (from 2010)</td>
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<td>Johannes Roth</td>
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<td>PARE</td>
<td>Marios Kouloumas</td>
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<td>Health Professionals</td>
<td>Tanja Stamm</td>
<td>Thea Vliet Vlieland</td>
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- Previous to the ExCo meeting, the chairs of the ESCA and the SCEHSR meet to exchange information and to ensure collaboration between the two committees
- EULAR Secretariat will undertake the creation of an institutional memory of all SC in the intranet to show at EULAR Web
- Research funding will be subject to clear procedures. Funding will be obtained via two streams, with the second being favoured:
  - Reactive response to incoming proposals (e.g. recommendations, standardisation, databases, Task Forces, subcommittees); deadlines 01/01 and 01/07; forms available at EULAR secretary
  - Pro-active calls: orphan-disease program as a model; now: patient-reported outcomes, pain; formalised application process, peer-review
- There will be Research-oriented workshops in preparation for FP7
- EULAR has required from each national society to appoint a permanent liaison officer in each country to facilitate communications, which are otherwise disrupted with each presidential change.
- Next EU presidency (July-Dec 2010) will be in Belgium and it is their objective to have a focus on MSK and respiratory diseases. There will be a presidential meeting in October in Brussels. EULAR will present the “Brussels declaration”
Ongoing projects

Task Force on new criteria for RA, additional application

- Convenors: Daniel Aletaha / Gill Hawker
- Publication "The 2010 American College of Rheumatology / European League Against Rheumatism Classification Criteria for Rheumatoid Arthritis" approved by Executive Committee 02/2010
- New application on development of radiographic criteria: “How to define erosiveness for the new ACR/EULAR criteria”
  - Project leader: Désirée van der Heijde
  - Aim: Prevent patients from being falsely classified as having RA → high level of specificity
  - Content of definition: Magnitude of minimum erosion, no. of erosive joints, which joints.
  - Work packages:
    i. Literature review on the specificity of erosions in UA for diagnosis of RA (esp. specificity and cut-offs)
    ii. Analysis of 2 early arthritis cohorts (Leiden and ESPOIR) concerning specificity and sensitivity of different criteria
    iii. Testing of the different criteria in defined joint groups
    iv. Presentation to sub-task force

Task Force on biologics registers in rheumatology

- Convenors: Johan Askling and Will Dixon
- Paper on points to consider accepted by Annals 02/2010
- Final implementation workshop in Winter 2010. Persons interested to participate can contact Caroline Pasche (caroline.pasche@eular.org)

EUMUSC.NET Project

- Convenor: Anthony Woolf (UK)
- More information at http://eumusc.net/
- Major Work Packages:
  - Musculoskeletal health status in Europe (Woolf, UK; 1 year)
  - Standards of Care (Smolen, Austria; 15 months)
  - Musculoskeletal Conditions and Health Care Quality Indicators (Petersson, Sweden; 19 months)
  - Barriers and Facilitators to better musculoskeletal health (Uhlig, Norway; 13 months)
European Musculoskeletal surveillance and information network (Woolf, 3 years)

- Funding: EU: 987.700 €, EULAR: 300.000 €

**Agenda for presentation of the SC to Eular delegates in Rome**

**Rheumatology Update – Standing Committee on Epidemiology**
Friday, 15:45-17:15 Hall 10 – Room C

1. Alan Silman: The new ACR/EULAR criteria for RA – next steps
2. Johan Askling: EULAR task force on biologics registers: Results and further perspectives
3. Laure Gossec: Perspectives in patient-reported outcomes
4. Anthony Woolf: How can we use epidemiological data to influence policy? Joint EULAR, EU and WHO projects

**Status of EULAR repository of research databases (Loreto Carmona)**

- Convenor: Loreto Carmona
- The main objective is to create and to maintain a repository of databases of European Studies of rheumatology. The repository does not contain patient data, but describes the database, the criteria for entry, the data fields, any monitoring and reporting of individual or aggregated data.
- It also provides the names of PIs of longitudinal observational studies. Very helpful to look for collaborations and for additional data.
- There are 52 databases included. Still your collaboration is needed: identify cohorts in your country and give them the link to the repository or send an e-mail to repository@ser.es
- More information at [http://repository.ser.es/index.html](http://repository.ser.es/index.html)
- Each summer a medical student helps searching for cohorts, contacting PIs, and checking data, keywords, etc.
- The funding ended last year. We have applied for ongoing maintenance support. A young researcher / medical student from any country could rotate at the Research Unit of the Spanish Society of rheumatology if we get the funding for it. We will post it.

**Collaboration with the SC on Clinical Affairs (SCCA)**

- The SCCA has repeatedly asked for a list of clinical epidemiologists / methodologists that could help in their projects, mainly recommendations and classification criteria.
- Please, provide Angela Zink a list of clinical epidemiologists in your country that would be able to lead groups of around 20 people and with experience in methodology of consensus and development of criteria.

**Introduction to EMEUNET (Laure Gossec)**

- The network for young researchers within Eular, also known as EMEUNET (Emerging Eular Net) was created on the need to foster the collaboration of young researchers in recommendations, projects, etc. The core aims of EMEUNET are in harmony with EULAR objectives 2012:
Mission Statement: A working group of young clinicians and researchers in rheumatology: promoting education and highest quality research, widening collaborations and integrating with EULAR activities

- Principal objectives: 1) To enhance quality of research in European rheumatology; 2) To promote international collaboration; 3) To promote educational activities targeted to the young rheumatologist/trainee; 4) To facilitate participation/development of emerging Europeans in EULAR activities; 5) Highlight & address regional issues re. training and research opportunities

- EMEUNET encourages young rheumatology researchers from all backgrounds: clinical, translational, basic science

Formation of EMEUNET & Activities To date
- Daniel Aletaha/Maya Buchs/Laure Gossec initiated the concept
- Establish representation of most European Countries
- Formation of a working group
- First meeting held on 11th June (EULAR 2009)
- Identified and developed set of core principles, short- and mid-term goals
- Formal approval & recognition by EULAR executive committee March 2010

- EMEUNET: Achievements so far
  - Established EMEUNET mailing list
  - EMEUNET Business Meetings at least annually at the EULAR conferences
  - Establish EMEUNET Website within the EULAR website
  - EULAR Fellow’s session in Rome 2010:
    - Finding the Evidence (presentation by D. Van der Heijde)
    - Challenging the Journal Editor (joint presentation D Aletaha / T. Kvien)

- EMEUNET’s Educational Aims:
  - Educational Input for EULAR Conference
    - Contribute to educational content for trainees (member observing on the EULAR Standing Committee for Education)
  - Fellow/Trainee specific sessions at the EULAR:
    - e.g. research planning, career development/choices, presentation skills; career choices an initial topic 2010?
    - Moderation by a senior researcher with an EMEUNET committee member
  - EULAR postgraduate course
    - In close interaction with the chair of the EULAR standing committee for education:
      - Approach the national societies for formal recognition of the EULAR postgraduate course
      - BSR √ ; Other national committees tbc
    - Encourage financial support by the national societies to attend the course (tbc)

- Learning How Rheumatology is Shaped:
  - EMEUNET observer in the different EULAR standing committee
    - Each EULAR Standing Committee has an EMEUNET working group member acting as an observer
    - EULAR standing committees executives provide mentorship
  - Aim for EMEUNET:
    - Provide insight on how decisions are made on a committee basis
    - Become familiarised with the organisational work behind the scientific scenes

- EMEUNET’s Commitment to Interaction
Increase visibility of successful young researchers by
  - using the EMEUNET infrastructure and
  - the ties to the EULAR standing committee

Organise a social occasion for the EULAR abstract award winners with EMEUNET committee members
  - To acknowledge (and also celebrate) accomplishments of emerging researchers

Promote interaction between successful researchers

EMEUNET Plans for the Future

EMEUNET Event
  - Objective: to promote clinical and basic research in rheumatology by young researchers
  - Participants: emerging investigators in rheumatology (not limited to EMEUNET members)
  - Event: a two-day event (e.g. after EULAR congress to avoid travel costs)
  - Content: include scientific sessions (tbc) & breakouts
  - Time-frame: 2010-2011

Increase Website functionality (EMEUNET Interactive Website)
  - Virtual ‘blackboard’ for young European researchers
  - Facilitate exchange visits/sabbaticals to other European depts.
  - Promote research collaboration between individuals/centres
  - Provide transcripts of interviews of key opinion leaders
  - Publicise young abstract winners/grant successes etc
  - Time-frame: 2011-2012

Organisation
  - Steering committee
    - Daniel Aletaha (Austria), Maya Buch (UK) and Laure Gossec (France)
  - Working Group: Max. 20 persons (max.2/country). Criteria:
    - Rheumatologists/Allied Health Professionals
    - Evidence of research/educational activities/interest in EULAR activities
    - Maximum age of 40 years
  - Maximum 5 years
  - Join via application (CV/personal statement)
    - Selection by vote of existing committee members
    - Suggest incorporation of other meeting attendees – better country representation

Executive Committee

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**Communication**
- Via the EMEUNET webpage
  - Provide an online platform for international exchange by researchers with a “blackboard” section listing requests and proposals.
  - Highlight & address regional issues re. training and research opportunities
- Newsletter
  - Prepared twice a year
  - Include information relevant to emerging rheumatologists
  - Sent by email only to EMEUNET members

**Comments to EMEUNET from the SC**
- A Silman reminds the group about the Clinical Research Course that the SCEHSR had proposed in the past that did not have enough response. EUMUNET may translate this course to the rest of EMEUNET.
- F Guillemin comments that the course was intended to be mixed young and less young. It could be done with young rheumatologists and then expand to all.

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**Results of workshop on EULAR’s perspectives in patient-reported outcomes, preparation of a call (A Zink/L Gossec)**

- PRO EULAR working Group: Zink, de Wit, Gossec, Aletaha, Alten; Bijlsma; Boers; Carmona; Escorpizo; Guillemin; Kirwan; Mateus; Schett; Silman; Sokka; Stamm; Stucki; Kvien; Tennant.
- Background:
  - 2009 – EULAR approached to support translation of PROMIS
  - Nov 2009 – meeting initiated by the Epidemiology Standing Committee (Angela Zink).
    - Aims of the workshop: To define what should be the role of EULAR in supporting research and standardisation in the field of patient-reported outcomes
    - 12 experts from rheumatology/epidemiology and two patient representatives participated.
    - Compared to other fields of medicine, rheumatology is more advanced concerning multidimensional measurement of disease outcomes.
    - Need for further work:
      - Multiple questionnaires for each domain (accessibility)
      - Psychometric properties not always tested
      - Some diseases have aspects not assessed (eg Sjogren, hand OA...)
      - Development and validation of new PROs/personal life impact measures if insufficiently covered by available instruments.
      - Framework of the ICF
      - Disease specific or generic?
      - Patient involvement
    - Existing PROs:
      - Need for a toolbox with all questionnaires readily available, with their translations (EULAR? OMERACT?)
• PROMIS project: large databank, computerised adaptative testing (CAT)
• Translation and cross cultural validation
• Evaluation of PROs as potential treatment targets or as part of therapeutic algorithms, and their prognostic value in general.
• Evaluation of the position of PROs as opposed to standard / traditional outcomes in rheumatic diseases, especially in regard to improving patient care.
• Cut-offs:
  o OMERACT 2010: more work needed on Patient Acceptable Symptom State:
    ▪ Phrasing and answer options
    ▪ Variability (disease duration)
    ▪ Stringent cutoffs
    ▪ Sustainability of desired state
    ▪ Methodology
  o OMERACT 2010: more work needed on change:
    ▪ minimal change;
    ▪ detectable change;
    ▪ relevant (clinically important) change (but also depends on efficacy/toxicity context)
    ▪ Improvement cutoffs versus worsening cutoffs
    ▪ Methodology
  o EULAR Call for projects
    ▪ Develop a call for proposals
    ▪ Funding not defined as yet
    ▪ Task of the PRO group: to define scope and selection methods for such a call (proposal zu ExecCo)
• Scope:
  o Toolbox with all questionnaires readily available
  o Psychometric properties of existing questionnaires
  o Translation and cross cultural validation
  o Development and validation of new PROs
  o Prognostic value of PROs
  o Patient Acceptable Symptom State, MCID
  o Other areas relevant to PROs.
• Several projects to be funded
• Strongly encouraged/preferred
  o Multi center
  o Patient partnership
• Starting date 2011-2013
• Assessment of progress after 24 months
• Management:
  o Application
  o 4 external reviewers per project (1 is a patient)
  o Grant Advisory Council (GAC) decision:
    ▪ 2 practicing clinical rheumatologists
    ▪ 2 research methodologists/clinical epidemiologists
    ▪ 2 patient representatives
    ▪ 2 health professionals representatives
    ▪ EULAR President or representative
- 1 non-voting staff member

- **Comments to PROs Call from the SC**
  - K Tascilar highlights the importance of the presence of psychologists in the research teams.
  - There will be a call on pain by the end of October from the SCCA.
  - F Guillemin asks whether there is any prevision of how many projects will be submitted.
  - A Silman asks about the total budget. A Zink says it is not yet known.
  - F Guillemin highlights the importance of advertising correctly to reach all interested ones. It will be the task of national societies and of us.

Loreto Carmona, July 2010