

eular

fighting rheumatic & musculoskeletal diseases together

ESCEHSR Business meeting 2019

Laure Gossec (chair ESCEHSR), June 2019

eular

fighting rheumatic & musculoskeletal diseases together

The incoming chair

eular

fighting rheumatic & musculoskeletal diseases together

Announcements from EULAR Executive Committee

Update from the 2019 congress

eular

fighting rheumatic & musculoskeletal diseases together

Over 14,000 participants coming from 130 countries

Close to 5000 abstracts, 45% accepted for presentation

350 oral presentations

2200 posters

EULAR ABSTRACT SUBMISSION

eular

fighting rheumatic & musculoskeletal diseases together

4041

4109

4845

5069

3872

4323

4869

SCIE: 4551+51

HPR: 254+3

PARE: 64+1

TOTAL: 4924

+ LB: 27=4951

eular 2013

eular 2014

eular 2015

eular 2016

eular 2017

eular 2018

eular 2019

EULAR 2019 ABSTRACT SUBMISSION

eular

fighting rheumatic & musculoskeletal diseases together

45

4(5)

(30)

29

4(2)

(44)

38

(65)

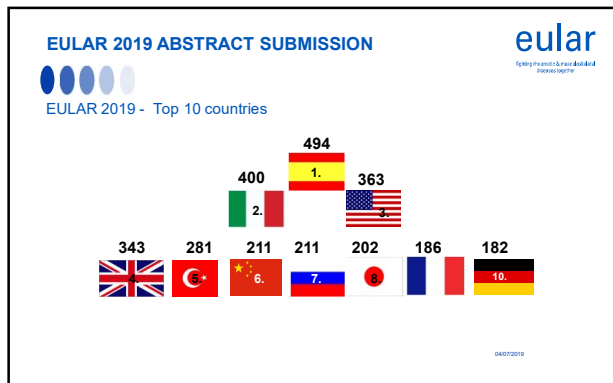
2805

(2846)

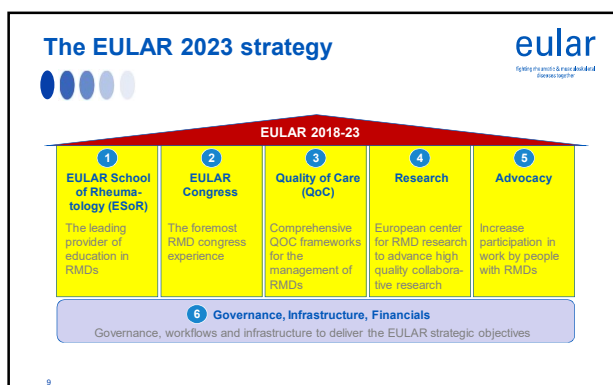
1044

(1208)

1



- ### Update from EULAR Exec
- Elections on Wednesday of new President Elect and new Treasurer
 - Restructuration of the EULAR Exec and Standing Committees and of funding decisions (better integration in the Strategy)
 - Specific meeting with Presidents of Scientific Societies (N=30) in March 2019 to improve communications
 - Suggestions include a platform for national societies, be involved in taskforce participant choice, congress session for best practices, give each national society a few free places for young rheumatologists



- ### The EULAR virtual research centre
- Setting up a research structure**
 - No funding of research, facilitator and enabler incl SOPs, expertise etc
 - Aiming for less disparity within Europe
 - Epidemiology and clinical research:** work in progress
 - Basic science:** work in progress
 - Clinical trials:** work more advanced
 - Focus on investigator initiated trials
 - Enabler for research by prioritization and support
 - Support of preparation conduct and reporting of clinical trials
 - Set standards for high quality trials
 - Deliver economy of scale for clinical trials

fighting rheumatic & musculoskeletal diseases together

EULAR Advocacy in Brussels and Beyond

Public Affairs Liaison Officers
Gerd Burmester (as of June 2019)
Neil Betteridge

EULAR Public Affairs Group (Core)

Neil Betteridge

Sören Haar
Federico Torres

Hans Bijlsma
Iain McInnes
Annamaria Iagnocco
Gerd Burmester
Julia Rautenstrauch

Dieter Wiek
Tanja Stamm

Laure Gossec
Francis Berenbaum
Loretto Carmona
Steffen Gay
Tony Woolf

EULAR Public Affairs Liaison Officer

European Affairs
European Affairs

President
President Elect
Treasurer
Past President
Executive Director

Vice President PARE
Vice President HP

France
France
Spain
Switzerland
UK

Link also with the BioMed Alliance

Collaborations with EMA, Horizon Europe etc

Also criteria for CME

EU Public Affairs Plan



eular
fighting rheumatic & musculoskeletal diseases together

EU Public Affairs Plan:

- Defines general and policy-specific goals for EULAR Public Affairs for the period 2019-2023
- Proposes success indicators
- Describes action lines and main initiatives
- Main focus:
 - Campaign on work participation for people with RMDs

EULAR advocacy



eular
fighting rheumatic & musculoskeletal diseases together

- "Time2work" current priority
- Positions and recommendations
 - Aim: Development of evidence, narratives and policy recommendations to use in PA actions
- Advocacy actions, events and meetings, European Parliament
 - Aim: Engage with policy makers and stakeholders in discussions to present EULAR's positions and recommendations
- Brussels conference in October (World Arthritis Day)
 - Success in 2018
 - Planned 2019, Facilitating the participation of people with chronic diseases in social and economic life. What is the role of EU health policies?

WAD Conference 2018: Position paper



eular
fighting rheumatic & musculoskeletal diseases together

- **Main goal:** Policy recommendations on health innovation in research and healthcare
- High level speakers from EU institutions and health & scientific community
- 130 participants in Brussels
- Large online audience

EU Parliament Interest Group on Rheumatic and Musculoskeletal Diseases



eular
fighting rheumatic & musculoskeletal diseases together

The European Parliament Interest Group on Rheumatic and Musculoskeletal Diseases (RMDs) was created in 2009 on the occasion of World Arthritis Day (12 October) and was re-established during the current parliamentary term (2014-2019).

The Interest Group (IG) is currently comprised of 22 Members of the European Parliament (MEPs) from different political groups, nationalities and committees. On average, the IG meets three times per year. EULAR runs the secretariat of the IG, providing support for its leadership and all members.

The Interest Group is led by:
 Roberta Metsola (Malta, European People's Party) – Chair
 Dr Soledad Cabezon Ruiz (Spain, Socialists & Democrats Group) – Vice-Chair
 Takis Hadjigeorgiou (Cyprus, European United Left - Nordic Green Left) – Vice-Chair
 Nathalie Griesbeck (France, Alliance for Liberals and Democrats for Europe) – Vice-Chair

- Interested in promoting EU policy initiatives aiming to better prevent and treat RMDs
- To ensure the social and economic inclusion of people with disabling or impairing RMDs
- To promote parliamentary actions on RMD-related policy issues
- To facilitate the discussion with other EU policy makers, stakeholders and experts on ongoing and future policy developments.

WHO and RMDs



Key facts

- Musculoskeletal conditions are the second largest contributor to disability worldwide, with low back pain being the single leading cause of disability globally.
- Musculoskeletal conditions and injuries are not just conditions of older age – they are relevant across the life-course. Between one in three and one in five people live with a painful and disabling musculoskeletal condition.
- Musculoskeletal conditions significantly limit mobility and dexterity, leading to early retirement from work, reduced accumulated wealth and reduced ability to participate in social roles.
- The greatest proportion of persistent pain conditions is accounted for by musculoskeletal conditions.
- Highly prevalent among multi-morbidity health states, musculoskeletal conditions are prevalent in one third to one half of multi-morbidity presentations, and very commonly linked with depression.

WHO response

WHO recognises that musculoskeletal health conditions contribute greatly to disability across the life-course in all regions of the world. In particular, WHO recognises that musculoskeletal conditions significantly impact functional ability.

<https://www.who.int/mediacentre/factsheets/musculoskeletal/en/>

eular
fighting rheumatic & musculoskeletal diseases together

Annals of the Rheumatic Diseases



- Journal belonging to EULAR since 1999 (50%), Editor : Josef Smolen
- IF 2017: 12.35. Now 1st journal in rheumatology (original research). Top 2% of journals worldwide
- Current acceptance rate ~13%, instant rejection 65%
- Recent evolution: 3 additional sections in editorial-type format: "Views on news" (5 done) / "thinking the unthinkable" (1 done) / "Heroes and Pillars of Rheumatology" (5 done)

RMD Open



- About 250 submissions per year and increasing, 118 accepted in 2018
- Acceptance rate around 35%, instant rejection 38%
- Impact factor planned 2020, paying submissions

FOREUM

- Next call 2020: gender differences in RMDs



Discussion point

- Structure and functioning of the EULAR Standing Committees
- Ideas, suggestions?

eular

fighting rheumatic & musculoskeletal
diseases together



Report from the Scientific Committee
for EULAR 2020

**EULAR 2020 Frankfurt,
Germany 3–6 June 2020**

eular

fighting rheumatic & musculoskeletal
diseases together



Study groups

ESCEHSR study groups



- Public Health of RMDs (Suzanne Verstappen UK)
- Epidemiology (A Finckh Switzerland)



EULAR Public Health of RMDs study group



EULAR Study Group on Epidemiology

Who we are <ul style="list-style-type: none"> Rheumatologists, health professionals, statisticians, epidemiologists interested in clinical research using observational data Aim of the Study Group <ul style="list-style-type: none"> To create a platform for methodological, logistic, and scientific collaboration across European Rheumatology observational researchers The aims are to maximise the potential use of the data collected within national registries, to maximise the quality of the scientific output, and facilitate the exchange of experiences across registries and researchers 	What we do <ul style="list-style-type: none"> Completion of several collaborative studies on adverse events in relation to biological anti-rheumatic therapies^{1,2} Completion of several collaborative studies on the effectiveness of bDMARDs³⁻⁵ Ongoing collaborative research : <ul style="list-style-type: none"> OMOP common data models (Daniel Prieto, FOREUM) Completed EULAR Task Force on data harmonisation and core set of variable for various diseases⁶⁻⁸ Ongoing EULAR Task Force groups: <ul style="list-style-type: none"> Big Data and Digital Health (L.G.) Points to consider when analysing and reporting comparative effectiveness (DC) 	References <ol style="list-style-type: none"> 1. Morone U, Aletti D, Rombaut P, et al. Effect of disease-modifying antirheumatic drugs on patients with rheumatoid arthritis treated with biological agents: results from a collaborative project of 11 European biologic registries. <i>Annals of the Rheumatic Diseases</i> 2017;96:202-207 2. Morone U, Rombaut P, Aletti D, et al. Spectrum of lymphoma across different drug treatment groups in rheumatoid arthritis: a European register collaborative project. <i>Annals of the Rheumatic Diseases</i> 2017;96:220-225 3. Langer R, Blugnegger G, Aletti D, et al. Drug selection of biological DMARDs in rheumatoid arthritis patients: the role of baseline characteristics and disease activity. <i>Arthritis Rheumatology</i> 2018 4. O'Sullivan D, Aletti D, Rombaut P, et al. Rheumatoid arthritis patients: the relation of co-morbidities and treatment of disease activity in a large multinational cohort study. <i>ESR Abstracts</i> 2018 Sep 17:302-305 5. F. Aletti, D. Carmona, et al. Study aims: does not report the clinical response in patients with rheumatoid arthritis. Analysis from the "EULAR register collaborative for adverse" (PRADA). <i>Clin Rheumatol</i> (2017) 36:173-179 6. Rafteri N, Chalkiadaki K, Nikiphorou G, et al. 2017 EULAR recommendations for a core data set to support observational research and clinical care in rheumatoid arthritis. <i>Annals of the Rheumatic Diseases</i> Published Online First 26 January 2018 7. Chalkiadaki K, Aletti D, Rombaut P, et al. 2018 EULAR recommendations for a core data set to support observational research and clinical care in psoriatic arthritis. <i>Arthritis Rheumatology</i> 2018 Sep 17:302-305 8. Rafteri N, Chalkiadaki K, Nikiphorou G, et al. The 2017 EULAR recommendations for a core data set to support observational research and clinical care in rheumatoid arthritis. <i>Ann Rheum Dis</i> 2018 Apr 17:169-170
--	--	---

eular

fighting rheumatic & musculoskeletal diseases together

Courses

ESCEHSR courses

- Health Economics Course (F Guillemin, B Fautrel):** 2nd edition took place 5 – 6 April 2018, 21 participants, very high satisfaction (mean, 9.4/10), on budget, next course planned in 2020
- Epidemiology Course (P Machado, L Gossec):** 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 in 2020
- Registries and Observational Data (RODS) Course:** 3rd course planned October 2019, Netherlands (cancelled in Oct 2018).

3rd EULAR HEALTH ECONOMICS IN RHEUMATOLOGY COURSE

Location: to be announced

EULAR SCHOOL OF RHEUMATOLOGY

Organisation and Faculty

Scientific organizers

- Pr Francis Guillemin & Pr Bruno Fautrel

Faculty members:

- Pr Annelies BOONEN, Maastricht University, Netherlands
- Maarten de Wit, Vrije Universiteit Amsterdam, Netherlands
- Pr Bruno FAUTREL, Sorbonne Universités, Paris, France
- Pr Francis GUILLEMIN, Université de Lorraine, Nancy, France
- Pr Manuela JOORE, Maastricht University, Netherlands

Learning objectives:

- To understand the principles of the economic analysis in health service research area, with application to musculoskeletal disorders, and to understand drug pricing

26-27 March 2020

eular

fighting rheumatic & musculoskeletal diseases together

RODS course

3RD Eular registers and observational drug studies course - Eular RODS

Organisers: Loreto Carmona & Elena Nikiphorou

Aim + key objectives

- To provide insights into key practical and methodological aspects relating to registers and drug observational studies, appropriate data handling and analysis of generated output, and to think collectively in future directions.

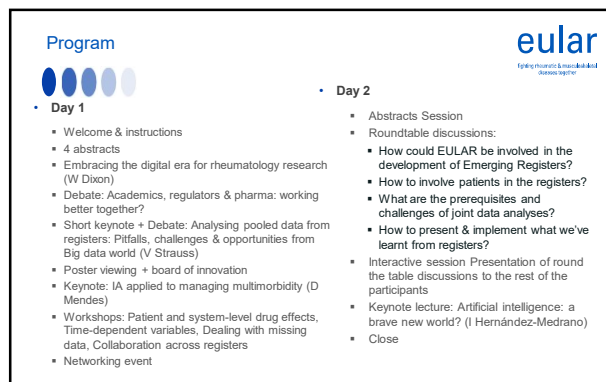
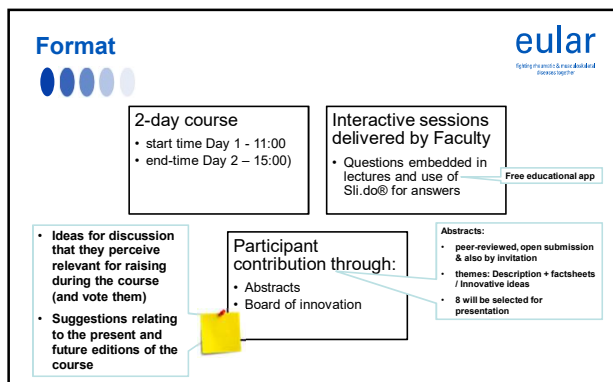
2 day interactive course with abstracts, board of Innovation etc

Date and place: 18-19 Oct 2019, Amsterdam Airport Hotel

Aimed at researchers and rheumatologists, registries, pharma, fellows

This is a 200 people course

Book soon!



ESCEHSR finished projects as of June 2019

Number	Project title	Convenor, epidemiologist	Date of start
EPI0 18	EULAR points to consider for Big Data in RMDs	Laure Gossec / Tim Radstake	2018
EPI0 22	Development of recommendations for a core data set for pregnancy registers in rheumatology	Anja Strangfeld / Rebecca Fischer-Betz, A Zink	2018

34

EULAR points to consider for Big Data in RMDs

Strategic Objective 3, 4, 5

Convenors/methodologist L. Gossec (France), T. Radstake (NL)

Aim: to develop points to consider for Big Data in RMDs: to cover data sources, data analyses and data interpretation and implementation

Methods: non-systematic literature review and single consensus meeting with experts inside and outside the field of rheumatology.

Budget: 50,000 euros

Time frame: approved 2018, F2F February 2019, paper in press June 2019

eular
fighting rheumatic & musculoskeletal diseases together

Summary of EULAR points to consider for the use of big data in RMDs

Number	Point
1	The use of global, harmonised and comprehensive standards should be promoted, to facilitate interoperability of big data.
2	Big data should be Findable, Accessible, Interoperable, and Reusable (FAIR principle).
3	Open data platforms should be preferred for big data related to RMDs.
4	Privacy by design must be applied to the collection, processing, storage, analysis and interpretation of big data.
5	The collection, processing, storage, analysis and interpretation of big data should be underpinned by interdisciplinary collaboration, including biomedical/health/life scientists, computational and/or data scientists, relevant clinicians/health professionals and patients.
6	The methods used to analyse big data must be reported explicitly and transparently in scientific publications.
7	Benchmarking of computational methods for big data used in RMD research should be encouraged.
8	Before implementation, conclusions and/or models drawn from big data should be independently validated.
9	Researchers using big data should proactively consider the implementation of findings in clinical practice.
10	Interdisciplinary training on big data methods in RMDs for clinicians/health professionals/health and life scientists and data scientists must be encouraged.

26 [Secretariat will add link of recommendation once available online on BMJ portal.] Gossec L et al. Ann Rheum Dis 2019 in press

EULAR recommendations for a core data set for pregnancy registers in rheumatology



- **Convenor/methodologist** Anja Strangfeld and Rebecca Fischer-Betz (Germany), A Zink (Germany)
- **Aim:** to develop a common core data set for data collected in observational research and clinical care of pregnancies in women with underlying IRD
- **Methods:** Endorsement of an ongoing initiative by the EuNeP collaboration of European pregnancy registers in France, Germany, Norway and Switzerland. Systematic literature research, face to face meetings, 2-round Delphi voting
- **Budget:** none
- **Time frame:** approved 2018. F2F in 2018, two Delphi rounds and final voting during F2F in 2019. Paper in preparation. Oral presentation at EULAR 2019, on Friday, 14 June **OP0326**.

Ongoing projects as of June 2019 (accepted 2018)



Number	Project title	Convenor, epidemiologist	Date of start
EPIO 18	EULAR Points to consider for lifestyle behaviour to prevent progression of Rheumatic and Musculoskeletal Diseases	Suzan Verstappen Francis Guillemin	2018
EPIO 20	EULAR points to consider when analysing and reporting comparative effectiveness research with observational data in rheumatology	Delphine Courvoisier / Axel Finckh, R Landewé	2018
EPIO 21	EULAR Points to consider when designing, analysing and reporting studies with work participation as outcome among patients with inflammatory arthritis	Annelies Boonen	2018

38

EULAR Points to Consider - Development of lifestyle behaviour recommendations to prevent progression of RMDs



- **Convenor/methodologist** S Verstappen (UK), Francis Guillemin (France), fellows James Gwinnutt (UK), Maud Wiecek (France)
- **Aim:** to develop points to consider identifying key recommendations for healthy lifestyle strategies to prevent the progression of specific RMDs and associated impact for the patient and society (e.g. disability, economic loss)
- **Methods:** systematic literature reviews and single face to face meeting.
- **Budget:** 50,000 euros
- **Time frame:** Accepted 2018, F2F May 2019, planned publication end of 2019

EULAR points to consider when analysing and reporting comparative effectiveness research with observational data in rheumatology



- **Convenors/methodologist** D Courvoisier and A Finckh (Switzerland), R Landewé (NL), fellow K Lauper (Switzerland)
- **Aim:** Develop EULAR points to consider to analyse and report effectiveness (e.g., treatment response rates) after a set time, correcting for confounding and attrition bias, and providing confidence intervals and p-values for group differences
- **Methods:** systematic literature review and single face to face meeting
- **Budget:** 55,000 euros
- **Time frame:** Accepted 2018, F2F February 2019, submitted to ACR 2019, planned publication end of 2019

EULAR points to consider when designing, analysing and reporting studies with work participation as outcome in inflammatory arthritis



- **Convenor/methodologist** A Boonen (NL), S Ramiro (NL), co-methodologist Polina Putrik (NL), fellows Mary Lucy Marques (PT), Marieke ter Wee (NL)
- **Aim:** Develop points to consider when designing, analysing and reporting studies with work participation as outcome
- **Methods:** systematic literature review and two face to face meetings
- **Budget:** 55,000 euros
- **Time frame:** Accepted 2018, 1st F2F February 2019, 2nd F2F meeting planned December 2019, end planned for June 2020

Ongoing projects as of June 2019 (accepted 2019)



Number	Project title	Convenor, epidemiologist	Date of start
EPIO 23	EULAR standardised operating procedures for Implementing recommendations	Estibaliz Loza, Loreto Carmona	2019
EPIO 24	EULAR Task Force to establish the evidence base and need for a EULAR Women's Network for Clinical Academics	Laura Coates Laure Gossec	2019

42

EULAR standardised operating procedures for implementing recommendations




Convenors/methodologists E Loza, L Carmona, JM Carrasco (Spain)

- Aim:** To provide guidelines on implementation for EULAR recommendations (as per EULAR strategic objectives)
- Methods:** 2 face to face meetings + SLR
- Budget:** 51,000 euros
- Time frame:** Accepted March 2019, invitation of SC (difficulties to find PRP), F2F planned October 2019, SLR ongoing

EULAR Task Force to establish the evidence base and need for a EULAR Women's Network for Academics

Strategic Objective 3



- Convenor/methodologist** L Coates (UK), L Gossec (France), fellow E Nikiphorou (UK)
- Aim:** To explore barriers and facilitators for women in academic positions in rheumatology (topic of gender disparity)
- Methods:** survey, meeting 1, survey, meeting 2
- Budget:** 48,500 euros
- Time frame:** Accepted March 2019, Survey July to Sep 2019, first F2F planned October 2019, and planned to finish by 2020 as planned

EULAR Task Force to establish the evidence base and need for a EULAR Women's Network for Academics: taskforce




Name	Country	Name	Country
1 Laura Coates	UK	12 Nemanja Danjanov	Serbia
2 Laure Gossec	France	13 Florence Apparailly	France
3 Pavel Ovsieko	UK	14 Caroline Ospelt	Switzerland
4 Laura Andreoli	Italy	15 Irene van der Horst-Bruinsma	Netherlands
5 Uta Kiltz	Germany	16 Elena Nikiphorou	UK
6 Leonieke van Mens	Netherlands	17 Katie Druce	UK
7 Neelam Hassan	UK	18 Zoltan Szekanecz	Hungary
8 Marike van der Leeden	Netherlands	19 Alexandre Sepriano	Portugal
9 Heidi Siddle	UK	20 Tadej Avcin	Slovenia
10 Alessia Alunno	Italy	21 George Bertsias	Greece
11 Iain McInnes	UK	22 Georg Schett	Germany

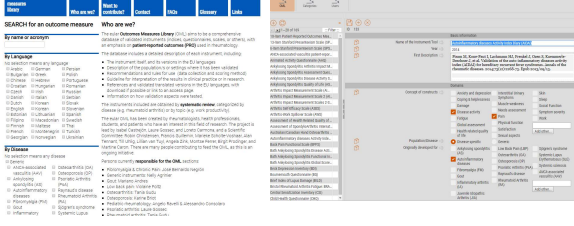

45 04/07/2019

Outcomes Measure Library

2019 Fellow
Alessandra Penati



169 PROs

fighting rheumatic & musculoskeletal diseases together

THANK YOU!

