EULAR

Epidemiology and Health Services Research Standing Committee

Business Meeting
June 2018

Agenda

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- Welcome and introductions
- Pedro Machado, Chair Elect of the standing committee – P Machado
- Report from the Scientific Committee – LG and A Finckh
- Announcements from EULAR Executive Committee: new EULAR strategy – LG
- Reports from SCEHSR Study Groups – S Verstappen, A Finckh
- SCEHSR Courses – F Guillemin, P Machado, L Carmona
- Ongoing projects- C Dejaco, F Buttgereit, S Verstappen, L Carmona
- New project: Big data – LG
- Any reports from individual countries

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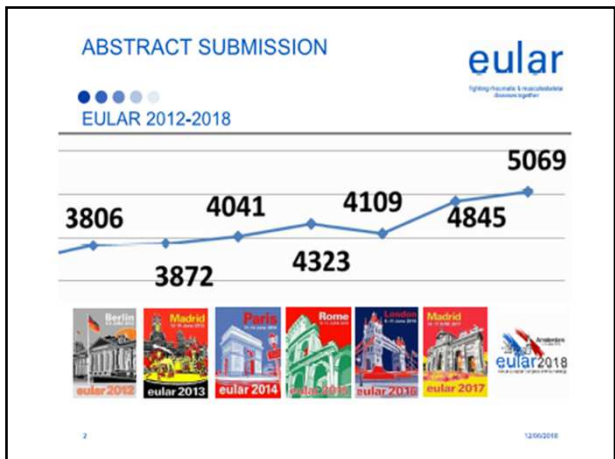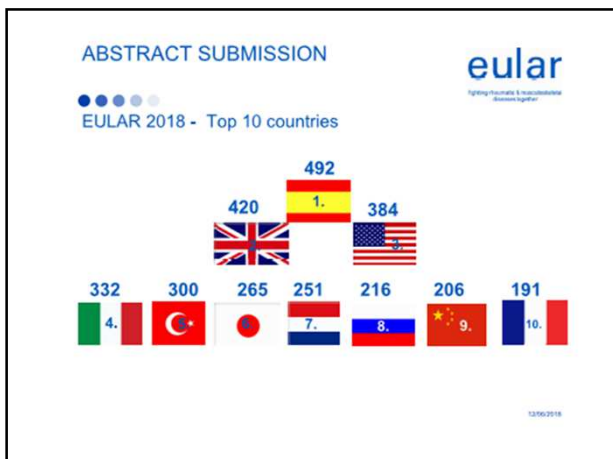- Any reports from individual countries

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EULAR Congress

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- **This congress (2018)**
  - More than 14,000 participants
  - More than 5000 abstracts submitted
  - 52% accepted (not counting AB only)
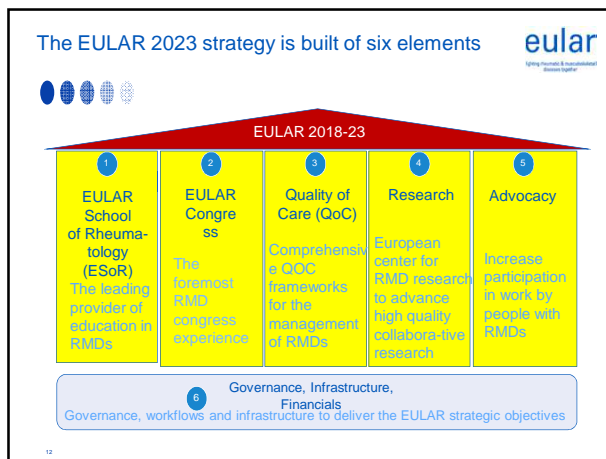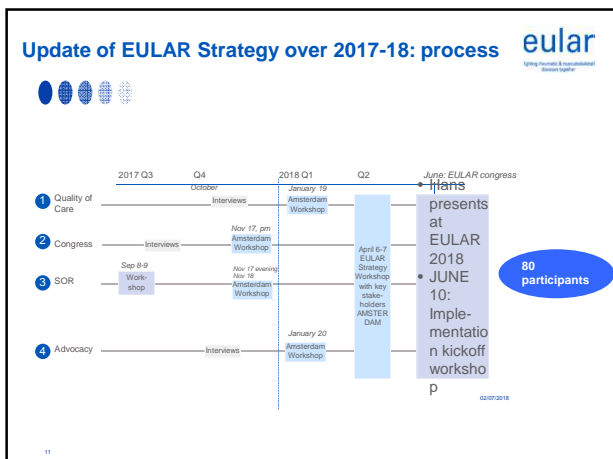 - 367 oral presentations, 435 poster tours, 1819 scientific posters

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ABSTRACT SUBMISSION

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EULAR 2012-2018

5069

3806   4041   4109   4845

3872   4323

Slide 1: ABSTRACT SUBMISSION — eular

EULAR 2018 - Top 10 countries

- 492 (1.) Spain
- 420 (2.) United Kingdom
- 384 (3.) United States
- 332 (4.) Italy
- 300 (5.) Turkey
- 265 (6.) Japan
- 251 (7.) Netherlands
- 216 (8.) Russia
- 206 (9.) China
- 191 (10.) France

Slide 2: ABSTRACT ACCEPTANCE — eular

TOP COUNTRIES 2018

Country	Oral	Poster	Poster Tour	O+P+PT	O+P+PT %	Publication	Rejected	Subm.
Spain	16	175	29	220	45%	167	105	492
United Kingdom	55	162	39	256	61%	97	66	419
United States	55	176	43	274	71%	75	35	384
Italy	22	131	32	185	56%	96	51	332
Turkey	3	106	7	116	39%	97	85	298
Japan	8	95	13	116	44%	105	44	265
Netherlands	47	104	42	193	77%	46	12	251
Russian Federation	2	63	9	74	34%	71	71	216
China	6	58	19	83	40%	79	43	205
France	23	89	18	130	68%	47	14	191
Germany	16	66	24	106	67%	35	17	158

Slide 3: EULAR Congress — eular

- **Next congress (2019)**
  - Madrid
  - Keeping 2 (3) subjects around epidemiology
  - No specific session (apart from our StC session) but possibility to propose cross-sectional sessions
  - 2 abstract sessions
  - 3 poster tours

Slide 4: Agenda — eular

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Slide 5: Update of EULAR Strategy over 2017-18: process — eular

Slide 6: The EULAR 2023 strategy is built of six elements — eular

EULAR 2018-23

1. EULAR School of Rheuma-tology (ESoR) — The leading provider of education in RMDs
2. EULAR Congress — The foremost RMD congress experience
3. Quality of Care (QoC) — Comprehensive QOC frameworks for the management of RMDs
4. Research — European center for RMD research to advance high quality collabora-tive research
5. Advocacy — Increase participation in work by people with RMDs
6. Governance, Infrastructure, Financials — Governance, workflows and infrastructure to deliver the EULAR strategic objectives

The full version of the 6 strategic goals for 2023

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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.

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Objective 1- ESOR: By 2023, EULAR will be the leading provider of education in rheumatic and musculoskeletal diseases (RMDs)

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- Using innovative learning methods and efficient content delivery according to learner needs
- Developing best learning offers based on state of the art educational practice and theory
- Improve access to quality education in the field of RMDs for all 3 EULAR pillars: rheumatologists, patients and HPRs
- Develop a recognised EULAR certification process to evaluate and document the acquisition of relevant knowledge.
- Making available the ESOR membership worldwide and offer benefits for individuals to connect with colleagues around the world and enhance knowledge and skills in the specific field as a rheumatologist, HPR or patient.

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Objective 2- Congress: By 2023, EULAR will provide the foremost RMD congress experience, building on the heritage of our outstanding annual meeting

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- Enhance congress experience by ..
  1. increasing interactive activities
  2. Increasing engagement of participants

- Increase online content placement option (e.g. e-Posters, e-Sessions, etc…)

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Objective 3 - QoC: By 2023, EULAR will deliver pre-eminent comprehensive quality of care (QoC) frameworks for the management of people with RMDs

Comprehensive quality of care (QOC) framework:

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

Education

Registries

Objective 4- By 2023, EULAR will have established a European centre for RMD research to advance high quality collaborative research.

- **Background**
  - **FOREUM (non profit research funding organisation)**
  - **RHEUMAMAP – research agenda for research**
- **Idea here**
- **Not research**
- **Facilitation of collaborative research: platform to stimulate collaborations and to support applications for financial support eg EU grants….**

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Objective 5- Advocacy: By 2023, EULAR's activities and related advocacy will have increased participation in work by people with RMDs

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Strategic content areas

- **Problem:** Employers are lack of awareness in RMDs (Either don't accept them or fire them) + Employees are stigma to share their conditions + RMDs youth are disadvantages to education (general)
- **Goals:** To educate or show diseases spectrum and convince them that it can be still managed
- **Target groups:** Employers, "Working place/ Employer-physicians & HPRs", OSHA, EC (soft policy for proper work behaviour), interesting to target with pharmaceutical companies, "working RMDs testimonials"

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Slide 1

Objective 6- Governance, Infrastructure, Financials: By 2023, EULAR will have established governance, workflows and infrastructure to deliver the EULAR strategic objectives.

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Governance
- Create transparency with respect to all (administrative) workflows
- Ensure full compliance with tax and legal requirements
- Achieve direct control of
  - data ("customers","internal" stakeholder)
  - processes (congress/course organisation)
  - finances (including congress/courses)
- Reduce dependency from third parties
- Facilitate leadership by establishing inhouse expertise
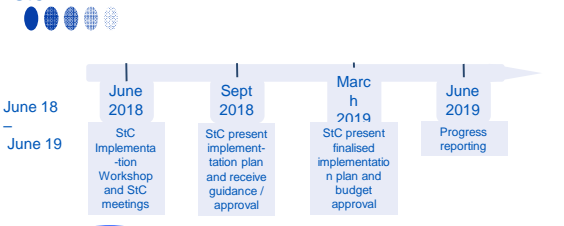
Infrastructure
- Evolve administrative and operational IT systems ensuring to be sustainable in the future and to fully support the strategy
- Use IT systems not only for administrative purposes, but also as a strategic tool
- Achieve and ensure direct control and processing of all data
- Facilitate networking of EULAR stakeholders (e.g., by IT support)

Financials
- Enable EULAR leadership to oversee and steer all financial affairs, tax, compliance and risk topics
- Facilitate transparency and direct control of EULAR's financial matters
- Ensure compliance with legal and tax requirements
- Build up inhouse expertise by establishing a dedicated financial department

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Slide 2

Next steps: Implement the EULAR 2023 Strategy by StC

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June 18 – June 19

June 2018	Sept 2018	March 2019	June 2019
StC Implementa-tion Workshop and StC meetings	StC present implement-tation plan and receive guidance / approval	StC present finalised implementation plan and budget approval	Progress reporting

Choose max 5 project ideas and link them to a strategic objective

Slide 3

What is ESCEHSR role in implementation of strategy?

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**Concentrate on one or two Strategic Objectives (proposals below)**

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. NOT YET STARTED

5. Advocacy: By 2023, EULAR's activities and related advocacy will have increased participation in work by people with RMDs.

Propose practical projects (one pager for Sep 10 including aim, methods, Convenor and budget if possible: aim for 50k-100k euros)

Obtain acceptance/support and funding at Sep EULAR Exec meeting

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Slide 4

Objective 3 - QoC: By 2023, EULAR will deliver pre-eminent comprehensive quality of care (QoC) frameworks for the management of people with RMDs

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Education

Registries

Slide 5

Preliminary ESCEHSR proposals (1) Obj 3 QoC

Sub-objective	Background	Project Idea Description
Recommendations / Best practice guidelines	Many recommendations already Quality indicators for RA and OA by eumuscnet	Develop standards of care or quality indicators for axSPA /lupus /osteoporosis
Tools helping better implementation of guidelines into daily practice	Implementation is a huge issue!	- Need for implementation of recommendations study group - Need for taskforce with ideas to improve
Tools helping better implementation of guidelines into daily practice	Implementation also influenced by shared decision making. Many data on this but no consensus	Proposal of a SDM tool: SLR of tools and validity data, and either proposal/dissemination of a tool or development de novo of a tool
Provide best practice across countries	Unclear – maybe take into account diversity within eular for QoC?	Survey of QoC or of quality indicators eg in 100 patients per disease and per country?

Slide 6

Preliminary ESCEHSR proposals (2) Obj 3 QoC / 4 and 5

Sub-objective	Background	Project Idea Description
Outcome measurement	OML!	Continue OML! Who? What more?
Roles and responsibilities along the patient journey	Could cover SDM, adherence, self management….	L Carmona ongoing working group on adherence
Roles and responsibilities along the patient journey	Could cover SDM, adherence, self management….	S Verstappen ongoing project on healthy lifestyle
Roles and responsibilities along the patient journey	Public health for early diagnosis, role of HPRs, etc	Organisation of care project? By Public Health Study Group or other? Also to get involved in **Obj 5** (work – make a survey?)
Education	What is meant here (for QoC)?	?
Registries	Also relevant for **objective 4!**	Cross –registry collaboration or other ideas (Epi study group?)

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ESCEHSR study groups

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ESCEHSR Study Groups:
- Public Health of RMDs   (previously T Wolfe, now Suzanne Verstappen)
- Epidemiology   (previously RODS, W Dixon and J Askling, now Axel Finckh)

Public Health of RMDs (S Verstappen)

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- Suzanne Verstappen
- Poster at this congress
- Workforce /research project in relation with this Study Group

Epidemiology (A Finckh)

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- Axel Finckh
- Meeting at this congress

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ESCEHSR courses

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- Health Economics Course
- Epidemiology Course
- Registries and Observational Data (RODS) Course

Slide 1

2nd EULAR HEALTH ECONOMICS IN RHEUMATOLOGY COURSE

Organisation and committee

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

Supported by
* EULAR secretariat
* MCI
* Nancy *School of Public Health*
  Faculty of Medicine
  University of Lorraine

5 - 6 April 2018   Prague, Czech Republic

Slide 2

Course applicants
31 applications
21 attended
17 with bursary

Attendees from 16 countries.

Background: 2 patients (via PARE), 1 rehabilitation specialist, 16 rheumatologists (at least 3 via Emeunet), 2 scientists including one economist in training

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

Programme:
2 days on-site:
Interactive teaching and small group activities
+ 1 Webinar - Incorporating the patient's voice

Evaluation (0 to 10 scale)
* Lectures :   interest 9.3 [8.8 – 9.7]
                        quality 9.2 [8.9 – 9.5]
* Interactive workshops: 9.4 and 9.2

* Appreciation: "*Very well organized*", "*International attendance, with different backgrounds*", "*in a friendly atmosphere*". "*Teacher quality, clear and concise, adaptation to the audience, using simple approach for complex concepts*". They found the course "*comprehensive, very structured, appropriate*", and most quoted the quality of "*workshops, small group session, with positive stimulation, and hands-out*".

Perspectives:
Organizing the 3rd course in 2020
                  => EULAR School of Rheumatology
More workshops with practice and simulation exercises
Bursaries are highly appreciated

Slide 3

6th EULAR Epidemiology Course in 2018   eular

- **P Machado, L Gossec**
- **Same theme and speakers as 2017: Outcome measures**
  - Workshops on validity, reliability and responsiveness
- **Date: 29 and 30 June 2018 (2-day course)**
- **German Rheumatism Research Centre, Berlin, Germany**
- **34 planned participants**

- **Future courses under discussion**

Slide 4

3RD Eular registers and observational drug studies course - Eular RODS (L Carmona)   eular

- **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.
    - A pragmatic view
    - To discuss and learn from examples
    - To enhance networking and interaction
    - Insights into appropriate methods
    - Teaser for big data analyses

Slide 5

RODS Format   eular

2-day course
- start time Day 1 - 11:00
- end-time Day 2 – 15:00)

Interactive sessions delivered by Faculty
- Questions embedded in lectures and use of Slido® for answers

Free educational app

- Ideas for discussion that they perceive relevant for raising during the course (and vote them)
- Suggestions relating to the present and future editions of the course

Participant contribution through:
- Abstracts
- Board of innovation

Abstracts:
- peer-reviewed, open submission & also by invitation
- themes: Description + factsheets / Innovative ideas
- 8 will be selected for presentation

Slide 6

RODS Program   eular

- **Day 1:**
  - Welcome & instructions
  - 4 abstracts
  - Embracing a new era of digital space
  - Debate: Academics, regulators & pharma: working better together?
  - Short keynote + Debate: Analysing pooled data from registers: Pitfalls, challenges & opportunities from Big data world
  - Poster viewing + board of innovation
  - Keynote: Meta-analysis in the Big-data era
  - Workshops: Patient and system-level drug effects, Time-dependent variables, Dealing with missing data, Longitudinal data modelling
  - Networking event

- **Day 2**
  - Abstracts Session
  - Roundtable discussions:
    - How could EULAR be involved in the development of Emerging Registers?
    - How to involve patients in the registers?
    - How to pool data together for registers?
    - How to present & implement what we've learnt from registers?
  - Interactive session Presentation of round the table discussions to the rest of the participants
  - Keynote lecture: Artificial intelligence: a brave new world?
  - Close

RODS Practical information — eular

- **Course venue**
  - Hyatt Place Airport Hotel ****, Amsterdam

- **Course opening & closing**
  - 30th November – 1st December 2018

  This is a 200 people course. Book soon!

- **Course certification**
  - A certificate of attendance will be available 1 week after the meeting on your ESOR account.

News for future courses — eular

- **Courses to be organised in agreement with School of Rheumatology**
- **Due to VAT future courses will be in Spain or NL**
- **Organisation taken over EULAR itself (not MCI)**

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ESCEHSR projects — eular

Finished projects: published
- Symptoms in Persons At Risk of Rheumatoid Arthritis (SPARRA) questionnaire: development of a questionnaire (EPI013, Dirkjan van Schaardenburg)
  - van Beers-Tas Mh et al. Initial validation and results of the Symptoms in Persons At Risk of Rheumatoid Arthritis (SPARRA) questionnaire: a EULAR project. RMD Open. 2018 May 21;4(1):e000641.

Finished projects: not yet published
- Outcome measures for giant cell arteritis (GCA) registries - F. Buttgereit
- Need for rheumatologists assessment in Europe C Dejaco

Ongoing projects
- Healthy lifestyle (S Verstappen) – accepted March 2018
- Outcomes Measures Library – L Carmona

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EULAR Task Force: Core Set of data to be collected in GCA registries — eular

Convenor: Frank Buttgereit

Steering group:
- Johan Askling
- Hans Bijlsma
- Frank Buttgereit (Convenor)
- Will Dixon
- Lisa Ehlers (Fellow)

- **EULAR SOPs were followed**
- **Work will be presented at this EULAR congress, article in progress**

EULAR 'points to consider' for the conduction of workforce requirement

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studies in rheumatology

- Convenor C Dejaco
- Full group: Christian Dejaco[1,2], Polina Putrik[3], Julia Unger[4], Daniel Aletaha[5], Gerolamo Bianchi[6], Johannes W. J. Bijlsma[7], Annelies Boonen[3], Nada Cikes[8], João Madruga Dias[9], Louise Falzon[10], Axel Finckh[11], Laure Gossec[12], Tore Kristian Kvien[13], Eric Mattesson[14], Francisca Sivera[15], Tanja Stamm[5], Zoltan Szekanecz[16], Dieter Wiek[17], Angela Zink[18,19], Sofia Ramiro*[20], Frank Buttgereit*[19]

- The broad objective of this project was to provide EULAR endorsed 'points to consider' for the methodology of future workforce requirement studies for adult rheumatologists.
- EULAR SOPs were followed
- 2 abstracts have been accepted at this congress as posters/poster tours
- 2 articles are currently being circulated to EULAR Exec

ESCEHSR projects

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Healthy lifestyle (S Verstappen)

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- Project accepted in March 2018
- First meeting planned for end of the year

OML update

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- The EULAR Outcomes Measure Library (OML) is an in-progress structured library, led by rheumatologists, constructed thanks to a Eular grant in 2012.
- It includes patient reported outcomes (PROs) and other indices frequently used in rheumatology to evaluate treatment response and to guide clinical decisions.
- It is freely available online since November 2013 (http://oml.eular.org/) and connected to the main EULAR website.

OML update

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- Since 2017, the OML it is also available through the Eular App.
- The app includes also calculators of the most widely used indices.
- The Eular App can be downloaded at the Eular School of Rheumatology as part of the educational materials

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Big Data proposal

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- Big data: a key issue for research both clinical and basic
- Preliminary proposal (L Gossec, T Radstake):
- EULAR Roadmap for Big Data and e-health in rheumatology
- SLR and consensus meeting with experts inside and outside the field of rheumatology
- Points to cover ethical/pricacy issues, data sources, collaborations with Big Data partners, statistics and presentation of Big Data results
- Please contact Laure if interested

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