

InnovaBone Conference
Biomaterials for Bone Regeneration

Brussels, 14 October 2015

Engaging patients in EU policies and priorities

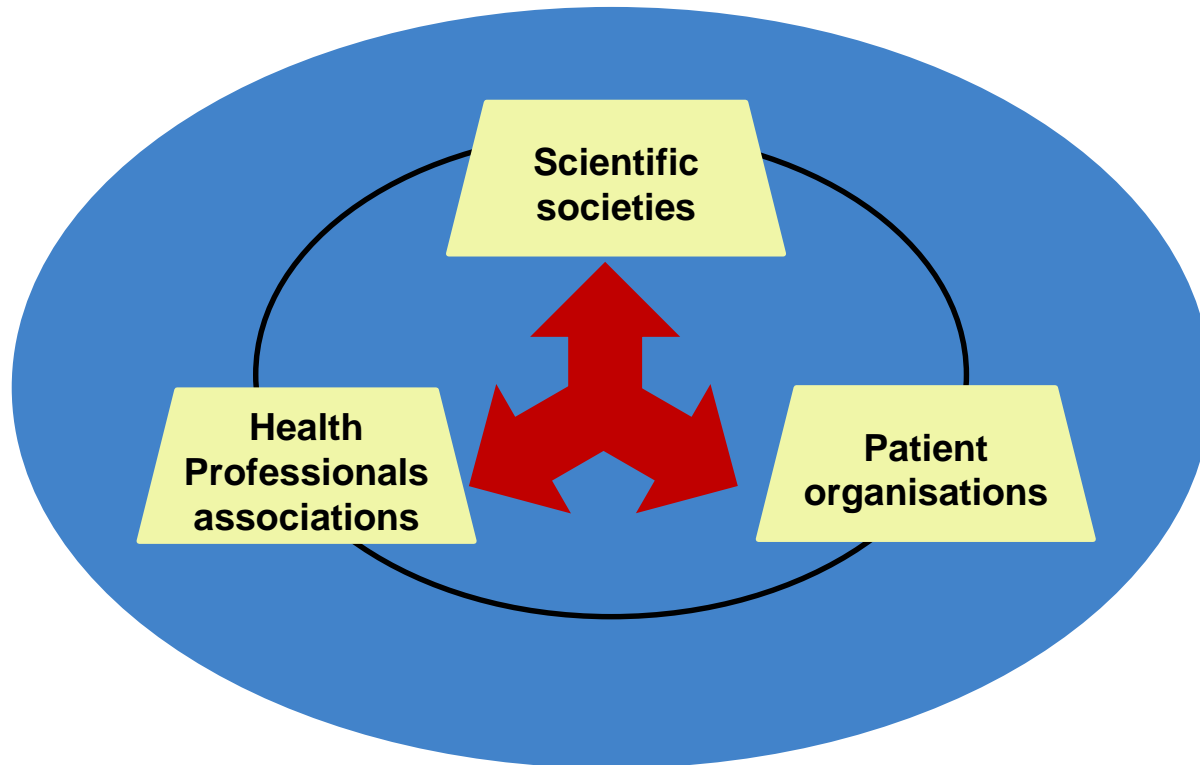
Neil Betteridge

EULAR Liaison Officer for
International Organisations, Public Affairs

eular

**All aspects of RMDs
(rheumatic and musculoskeletal diseases)**

Foundation: 1947



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About EULAR

EULAR mission:

- to **improve the treatment, prevention and rehabilitation** of musculoskeletal diseases; and thereby
- To **reduce the burden** of rheumatic and musculoskeletal diseases (RMDs) on the individual and society

Contribution to reducing the burden of RMDs

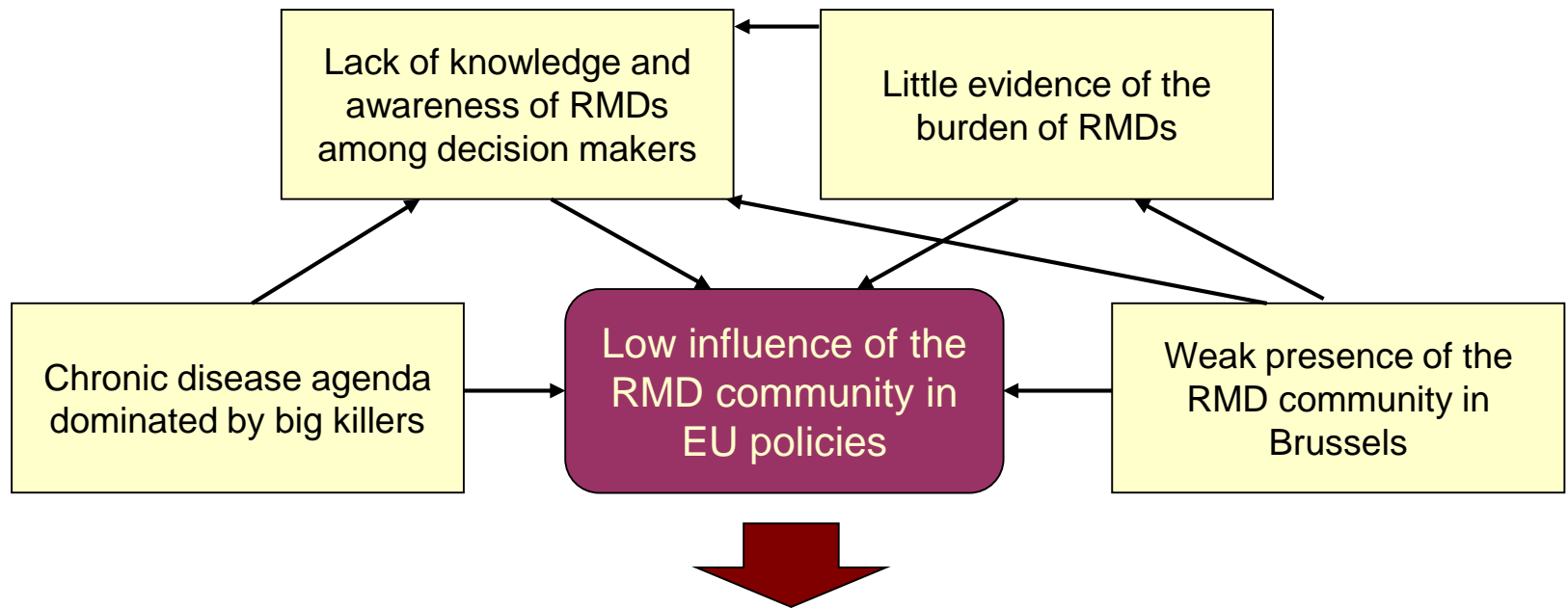


Research & Innovation

- Advice to policy makers and funding institutions on medical research policies
- Analysis of RMD research & innovation, identification of gaps, needs and priorities for the future
- Fundraising for research and innovation in RMDs and support to research projects (also in conjunction with FOREUM)

Advocacy

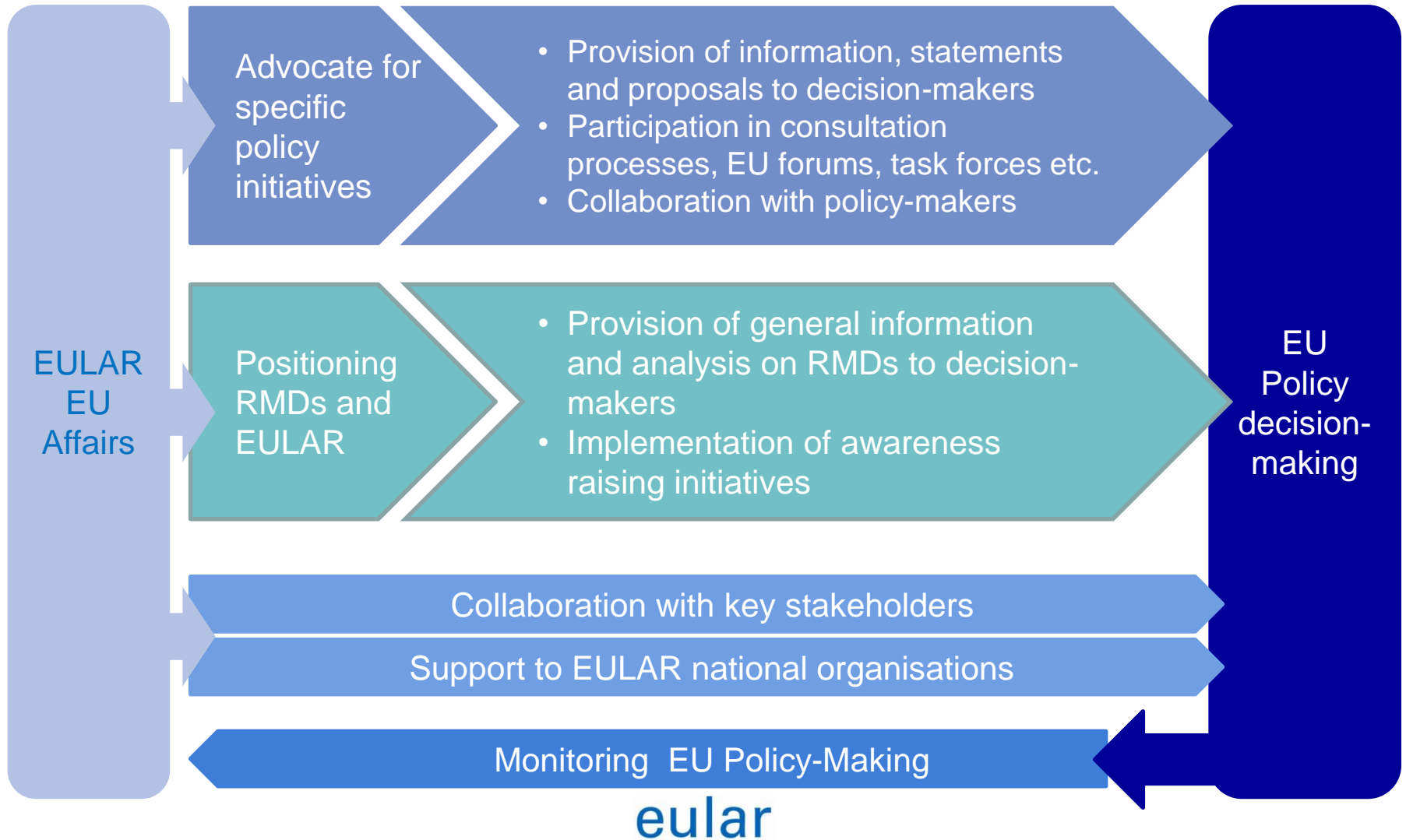
Situation of RMDs in the EU in 2005



- RMDs not seen as a priority or as a major chronic condition
- EU research & public health agenda mostly influenced by other chronic disease communities
- EU research funds not proportional to the burden of RMDs

Advocacy

EULAR EU Affairs



Advocacy

The position of RMDs and EULAR today

- RMDs starting to be recognised as a one of the major chronic diseases
- EU funds for research in RMDs have increased in the last years
- EULAR now has a high profile and strong reputation as the umbrella body for RMDs
- EULAR's opinion and collaboration are regularly sought by policymakers
- EU policies increasingly take account of the needs of the RMD community

Advocacy

Remaining challenges

- ✧ Insufficient knowledge and awareness about RMDs and their burden
- ✧ EU and other international organisations (WHO) still prioritise mortality, not morbidity and burden of diseases
- ✧ EU public health agenda still largely influenced by “big killers”
- ✧ EU research funds still not proportional to the burden of RMDs vis-a-vis other disease communities
- ✧ Insufficient social affairs and employment legislation
- ✧ Reluctance to implement specific, comprehensive strategies against RMDs at the EU level

Advocacy

Strategic objective 4 – Advocacy

By 2017, EULAR will have a significant influence on EU level, and assist actions on national level, towards improving research funding, social policy legislation, and quality of care.

By 2017, EULAR will have established that RMDs will be recognised at EU, national and global levels as equivalent to the other major diseases.

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By 2017, EULAR will have developed a widely coordinated public affairs strategy and a platform for both EU and national campaigning.

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By 2017, EULAR will be collaborating internationally on priorities such as age and disability related issues, rare diseases, and early diagnosis.

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Advocacy

Main policy goals

Research

- EU funds match the burden of RMDs
- Advice to EU institutions on medical research

Social Affairs

- Stronger laws on working conditions
- Action towards implementation of the EU Disability Strategy and UN Convention

Public Health

- Collaboration with EU on prevention and management of chronic diseases
- Implementation of eumusc.net recommendations

Advocacy

Main ongoing and upcoming advocacy actions

- Conference “Towards more integrated health care in Europe” (13 October 2015)
- EP Interest Group on RMDs (19 November 2015)
- Advocacy for more research in RMDs in Horizon 2020
- Identification of gaps, needs and priorities in RMD research and innovation for the next 10 years
- Advocacy for reduction of access barriers to health care for people with RMDs
- Advocacy for EU legislation and initiatives on health and safety at work

Support to patient organisations

Aims of People with Arthritis and Rheumatism in Europe (PARE)

- Develop strong networks of effective, user led organisations of people with RMDs
- Ensure the voice of people with RMDs is heard and acted upon by decision makers at the European level
- Create powerful alliances and collaborations inside and outside EULAR, which make a difference to the lives of people with RMDs
- Provide support to patient organisations

Support to patient organisations

Empowering EULAR/PARE members:

- Sharing of news & information
- Internal events / Training
- Support to national/EU advocacy campaigns
- Support to people with RMDs in EU advocacy actions

Two main levels of advocacy work:

Advocating
for concrete
policy results



Shaping the
political & policy
environment

Support to patient organisations

➤ Sharing of news & information



Breakthrough & E-Breakthrough



With one Voice



EULAR Directory of PARE Organisations



Stene Prize booklet



Information on EU policies and initiatives

Support to patient organisations

➤ Internal events / Training

- ❖ EULAR/PARE Autumn Conference
- ❖ PARE Programme at EULAR Congress
- ❖ Country Visits

Support to patient organisations

➤ Internal events / Training

Autumn Conference

2012: 150 delegates from 34 countries

Objectives:

- To inspire, educate and empower delegates and their national organisations to develop and execute campaigns
- To make delegates and their national organisations aware and receptive to the benefits of international collaboration



Support to patient organisations

➤ Internal events / Training

PARE Programme at EULAR Congress

- Annual event with c15,000 attendees
- Growing number of delegates from PARE
- Political campaigns topics are included



Support to patient organisations

➤ Support to national advocacy campaigns

Country visits

- Primary aim to support national member organisations
- Having official representation of EULAR when working at national level attracts high-level politicians and other key stakeholders to events

EULAR support to patients engagement in policymaking

➤ Support to national advocacy campaigns

Country visits: recent examples:

FYROM (2011) & Bulgaria (2012)

- Attracted European Commission and Parliamentarians
- Collaborative approach: national agenda and European perspective
- Political events: roundtables and press conferences
- Alliances established identifying obstacles in national environments and providing best practice solutions from European perspective.



EULAR support to patients engagement in policymaking

➤ Support to national advocacy campaigns

Country visits: outcomes

Bulgaria:

- Improved access to public authorities such as Ministry of health
- Identification of important stakeholders sharing concerns about major obstacles in Bulgarian system
- Signage of Brussels declaration by all important stakeholders attending the meeting - opportunities for follow up of national organisations.



Support to patient organisations

➤ Support to national advocacy campaigns

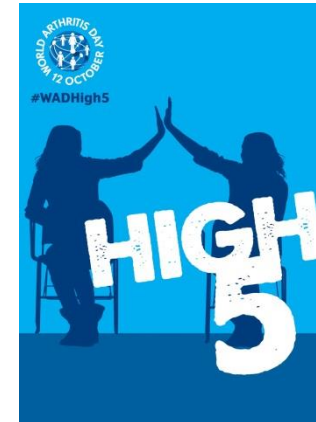
World Arthritis Day



**IT'S IN YOUR HANDS
TAKE ACTION**



- Global awareness-raising day, 12 October.
- EULAR organises activities internationally to complement activities at national level organised by PARE members (working with health professionals and clinicians)
- www.worldarthritisday.org



Support to patient organisations

➤ Support to people with RMDs in EU advocacy actions

Support in contacting EU policy makers:

- Identify the key policymakers
- Understand the political and policy context
- Develop tools and templates for adaptation nationally

Involvement of people with RMDs in the design and implementation of EU Activities:

- EULAR Brussels Conference and other events
- EULAR campaigns (e.g. EULAR Brussels Declaration, Horizon 2020, Access to Health Care, etc.)

Conclusion

Key concept for patient representatives is self determination

‘Nothing about us without us!’

The stronger the autonomy, the stronger the partnership with health professionals when uniting to influence the world!

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Questions or comments?