About the EULAR Annual European Conference of PARE:

Since 1997 a dedicated conference has been held for EULAR member organisations of PARE, which is hosted by a different country each year. This year’s Annual Conference was held in Malahide, County Dublin, Ireland and was hosted by Arthritis Ireland.

There were 150 delegates from 33 countries in attendance with over 30 young representatives (under 35 years of age). There were 25 attendees from Arthritis Ireland, with the majority of them being volunteers who were invaluable to the smooth running of the conference.

The overall conference topic followed the World Arthritis Day 2015/2016 theme of Patient Centred Care, ‘Taking Control’, with eight workshops on offer, each running twice, allowing delegates the opportunity to attend four different workshops. The workshops covered a range of hot topics including e-health services, self-management, the EULAR recommendations, campaigning for patient choice, skills training, shared decision making and two youth workshops.

The Task Force responsible for planning this year’s conference:

Hans Bijlsma, EULAR Treasurer
Snezhana Bozhinova, 2016 Bulgarian Team
Peter Boyd, 2015 Irish Team
Stephanie Casey, 2015 Irish Team
John Church, 2015 Irish Team
Frane Grubišić, 2014 Croatian team
Marios Kouloumas, EULAR Vice President representing PARE
Christina Opava, EULAR Vice President representing Health Professionals in Rheumatology
Ingrid Pöldemaa, PARE Board and representative of young people
Maarten de Wit, Task Force member

2015 EULAR Annual European Conference of PARE objectives

1. To inspire, educate and empower delegates and their national organisations to develop and execute campaigns around the topic of ‘Taking Control’ patient centred care through:
   - providing expert keynote speakers;
   - sharing best practices;
   - developing practical materials that can be adapted for national activities and meet national needs.

2. To make delegates and their national organisations aware and receptive to the benefits of regional, European and international collaboration by:
   - clarifying and promoting the activities and relevance of EULAR;
   - demonstrating how EULAR can support the interests of its member organisations at a national and local level.

Arthritis Ireland objectives

3. Raise awareness of rheumatic and musculoskeletal diseases (RMDs) and the work of Arthritis Ireland with politicians / the Irish government.

4. To use the event to reinforce support for our volunteer base and ensure greater support and engagement from new volunteers.

REPORT
18th EULAR Annual European Conference of PARE, Dublin, Ireland, 24th – 26th April 2015

150 delegates attended the conference in Dublin
The 2015 Annual Conference welcomes Ireland’s Minister for Health, embraces new media and sets its focus on patient centred care.

In his opening address, Marios Kouloumas, EULAR Vice President representing PARE, welcomed the delegates and speakers, announcing that, following the success of live streaming the plenary sessions at the 2014 conference in Zagreb, this year the scope of the live streaming was being extended to include more of the conference.

The opening addresses, presentations and panel discussion and, for the first time, a selection of the workshops and feedback sessions after Friday and Saturday’s workshops, were all live streamed and viewed in total 130 times online. Furthermore these sessions were also made available on YouTube following the event and by 29 May had been viewed 517 times.

This year, the plenary sessions also featured a Twitter wall, allowing delegates and the external audience to engage via Twitter using the official conference hashtag #pare2015. Twitter engagement during the conference was high; more than 1,250 tweets were shared during the conference, reaching a potential audience of approximately 152,647 people.

“In have arthritis but arthritis doesn’t have me.” the video explains the burden of arthritis fantastically #pare2015

A highlight of the conference was the attendance of guest of honour, Ireland’s Minister for Health, Dr. Leo Varadkar, who took time out of his busy schedule to join the opening session.

Prof. Hans Bijlsma, EULAR Treasurer, delivered the welcome on behalf of EULAR, providing a brief history of EULAR, its mission and an introduction to some of its activities.

John Church, CEO Arthritis Ireland, the host organisation, extended his thanks to Minister Varadkar for attending the opening of the conference and highlighted the prevalence of rheumatic and musculoskeletal diseases (RMDs) in Europe and the economic impact they can have if they are not appropriately managed. He stressed the important role patient groups can play in this through providing advocacy, support and education, and took the opportunity to showcase some of the impressive work that Arthritis Ireland does for people living with RMDs in Ireland.

Minister Varadkar extended delegates a warm welcome to Ireland and formally declared the conference open. His compelling speech highlighted the importance of dedicating resources and efforts to managing RMDs in Ireland. The Minister emphasised the role of patient centred care and discussed the cost-effective benefits of self-management, especially in chronic conditions such as RMDs.

“At have arthritis but arthritis doesn’t have me.” video

“I have arthritis but arthritis doesn’t have me.” the video explains the burden of arthritis fantastically #pare2015

The subsequent presentations by Claire Kinneavey and Prof. Hans Bijlsma introduced and reinforced the importance of patient centred care, echoing the theme of the conference.
Claire Kinneavy, Arthritis Ireland Volunteer and Master Trainer in Chronic Disease Self-Management, gave an emotional and powerful presentation on ‘RA self-management – a patient perspective’. Claire shared her personal experience of diagnosis and how she managed to reclaim her life, including the benefits she has gained as a volunteer with a local Arthritis Ireland branch before becoming involved in its self-management courses.

"Kinneavy says self management helped put ‘arthritis in the back seat’ rather than it being ‘an interfering front seat driver’ #PARE2015"

Prof. Hans Bijlsma, Professor of Rheumatology, Utrecht and Amsterdam, Netherlands and EULAR Treasurer, presented ‘An introduction to patient centred care’, discussing three different definitions: (i) no decision about treatment of a patient without the patient, (ii) every treatment modality puts the patient in the centre and (iii) personalised treatment. Hans gave a comprehensive overview of the difference between ‘Treat to Target’ and ‘Personalised Medicine’ and emphasised the role of patient organisations in addressing the information gap between doctors and patients.

Panel discussion

Following the opening addresses and presentations on Friday morning, Marios Kouloumas moderated a lively interactive panel discussion with Prof. Hans Bijlsma and Claire Kinneavy, who were joined by Boryana Boteva (Vice President, Bulgarian Organisation for Patients with Rheumatic Diseases), and Prof. Christina Opava (EULAR Vice President representing Health Professionals in Rheumatology). The panel agreed on the importance of patient centred care and discussed inequalities in different countries across Europe, with Boryana explaining that in Bulgaria there is as yet little or no knowledge or understanding of the concept.

Workshops, feedback and voting statements

Interactive feedback sessions were held following the workshops on Friday and Saturday. For the first time, workshop leaders presented their feedback using a number of statements relating to the discussions in their workshops. Delegates were then invited to vote on whether they agreed or disagreed with, or were unsure how they felt about each statement. This interactive voting session involved delegates holding up green (agree), orange (disagree) or white (unsure) voting cards.

John Church moderated the informal interactive workshop feedback session on Friday. A similar session was held on Saturday, moderated by Diana Skingle, Chairperson of the EULAR Standing Committee of PARE.

Marios Kouloumas moderated a lively panel discussion
Policy and campaigning

On Friday, the importance of the EULAR recommendations for use in empowering people with RMDs and in EULAR policy work was highlighted by Dr Maarten de Wit, Task Force member, in a workshop on the ‘Dissemination of EULAR recommendations’. The workshop was run with support from Nele Caeyers and Prof. Christina Opava and introduced the Guide to disseminating the EULAR recommendations, which will become available later in 2015. Delegates were asked to compare scientific and lay versions of the EULAR recommendations and interestingly, found it hard to see the difference. The consensus was that the lay versions are still relatively hard to understand and that further work is needed to ensure these recommendations are accessible and practical for use by national organisations and people with RMDs.

Delegates suggested that non-expert patients could be involved in the development of the lay versions of the recommendations to ensure they are clear to all.

Nele Caeyers, CEO of ReumaNet, provided a case study from Belgium, highlighting the difficulties faced when organisations need to translate the recommendations into lay versions, and the benefits of lay versions being provided by EULAR. Nele went on to illustrate how the recommendations are disseminated through different platforms in Belgium, including via the ReumaNet website, social media channels and magazines.

Delegates formed into three sub-groups to discuss (i) what can be done where there are no lay versions of the recommendations, (ii) what organisations can do with the lay versions of the recommendations, and (iii) how organisations can disseminate the recommendations.

The three voting statements that were presented during the feedback session were:

- EULAR should provide an English lay version for each of the recommendations it develops (unanimous agreement)
- If available, our organisation would certainly translate and disseminate the lay versions of EULAR recommendations (majority agreed)
- Lay versions should not only target patients, but also rheumatologists and health professionals (majority agreed)

On Saturday, another aspect of how patient organisations can get involved in policy work was demonstrated by Neil Betteridge, Liaison Officer, Public Affairs EULAR, in his workshop on ‘Campaigning for patient choice’, supported by Marios Kouloumas. The workshop started by discussing what is meant by patient choice and how it relates to person centred care. Marios Kouloumas delivered a case study on a campaign run by the Cyprus League Against Rheumatism (CYPLAR) on patient and physician choice in medication, in particular the prescription of biosimilars versus biologics. Marios outlined the actions taken by CYPLAR to ensure people with RMDs in Cyprus would continue to have access to the most appropriate treatment and were not automatically switched, interchanged or substituted with a biosimilar on grounds of cost. He described the strategies adopted by CYPLAR, how these were implemented and the outcomes of the campaign.

Neil used his UK case study to demonstrate two aspects of patient choice: availability, dealing with campaigns around the healthcare support and services requiring political change, and accessibility, involving campaigns to ensure individuals have help to access what is available.

The sub-groups addressed two key questions, (i) what is available in your country and (ii) how easy it is to access these services or support. The groups brainstormed ideas for how organisations could use campaigning, advocacy work or awareness-raising activities to
reduce the barriers to availability and accessibility. It was emphasised that empowering patients to know what exists and psychologically engaging them to be willing to fight for it, is key to implementing change. Patient groups and peer support can play a vital role in helping with this.

The four voting statements that the delegates were presented with were:

- Society loves causes which help children: we need to be more ruthless in using kids’ experiences to attract support (split vote; the majority agreed, but about a third were unsure or disagreed)
- PARE members’ success in promoting the ‘empowered patient’ model has turned non-assertive patients into victims (majority disagreed)
- The range of complex new therapies available makes choosing the right one increasingly difficult (majority disagree, but about a third were unsure or disagreed)
- Having an RMD makes you stronger (majority agree, but a few were unsure or disagreed)

Skills training and learning to engage with mobile health

Epp Adler led the first skills training workshop offered at a EULAR Annual Conference, which gave delegates the opportunity to learn ‘How to successfully chair a meeting or moderate a session’. This workshop was not only designed to help attendees to enhance their role within their organisation, but also to train up future moderators and workshop leaders for EULAR activities.

Epp led an engaging brainstorm on what can make a meeting good or bad, with delegates suggesting factors such as positive atmosphere and reaching a goal, or lack of time management and unsuitable number of participants respectively. The group moved on to discuss what makes a good leader and how best to organise a meeting.

Epp highlighted the importance of learning the difference between managing things and leading people. Another key learning was that leading is an attitude, as well as a skill. Good attitude can compensate for a lack of skill, but good skills do not compensate for a bad attitude.

The voting statement that culminated from this skills training workshop was:

- Skills training should become a more prominent feature of the EULAR Annual European Conference of PARE (majority agreed)
The voting statements presented in the plenary session were:

- Do you think we should develop EULAR recommendations for the development of e-health services and apps? (majority agreed)
- Would you use an app that tells you where to find resources useful for RMD around you? (majority agreed, but a few unsure and disagreed)

“Regions could work on shared ehealth Apps to share the costs #pare2015”

**Patient centred care**

Following on from Claire Kinneavy’s opening presentation, Gráinne O’Leary, Head of Service Development for Arthritis Ireland, facilitated a workshop on ‘Exploring what steps national organisations can take to help people self-manage’. Claire Kinneavy supported Gráinne in this engaging workshop that compared the benefits and challenges of conventional self-management courses with an online model. The team from Arthritis Ireland presented their brand new online self-management tool as a case study and gave an online demonstration. David McLean, who runs a number of highly successful e-learning modules for health professionals, and who developed the technology for the Arthritis Ireland online self-management course, provided workshop attendees with technical considerations and insights.

The delegates were then split into three sub-groups that each identified a topic from the discussion, for example resources or cost, and then brainstormed the barriers related to this issue as well as some potential solutions.

The voting statements from this workshop were:

- Online self-management programmes are the way of the future (majority agreed, but a few disagreed)
- Every person diagnosed with an RMD should be offered self-management training (unanimously agreed)

“Every person diagnosed with an RMD should be offered self-management training- Couldn’t agree more #PARE2015 #lifechanging”

Prof. Anne Stiggelbout led a workshop on ‘How organisations can help to educate people with RMDs and improve shared decision making’, with the support of Dr Maarten de Wit and Prof. Christina Opava. This workshop offered a version tailored for more experienced organisations and another for less experienced organisations. The workshop for more experienced organisations concentrated on gaining insights into the tools and implementation strategies that could help increase shared decision making. The workshop for less experienced organisations ascertained the current levels of shared decision making, and then brainstormed the barriers to implementation and the roles patient organisations can take to support implementation.

A key conclusion from the workshops was that any issues involving shared decision making between patients and doctors should not be addressed separately, but in conjunction, so that all parties are involved, aware and well-informed.

The statements brought back to the plenary for voting were:

- It is up to patients to make Shared Decision Making (SDM) happen (majority disagreed, but some agreed)
- There are many tools to support SDM, but they need to be better implemented (unanimously agreed)

“Shared decision making results in better decisions on care, fewer doctor visits, better satisfaction. #pare2015”

**Youth**

The first youth workshop, which looked at the ‘Young PARE strategy – from plan to action’, was led by Petra Bednarova, volunteer and board member of the Slovak League Against Rheumatism (SLAR), who joined the Young PARE taskforce in March 2014 and will become its first chair. She was supported by Linda van Nieuwkoop, chair of the Dutch organisation Youth-R-Well.com, and Jeanette Andersen, who was representing Lupus Europe.

Petra and Linda began the workshop by running through the eight Young PARE strategic objectives, discussing actionable steps for each one. Delegates were then given the opportunity to choose the three strategic objectives of most interest to their...
organisations, and three sub-groups then discussed each of these in more detail.

In the first workshop, the three prioritised strategic objectives were, (i) by 2020, educational institutions across Europe are more flexible and assistive in supporting high quality education of young people with RMDs, (ii) there is more awareness in society of the specific needs of young people with RMDs and employers, and (iii) other stakeholders are more aware of the needs of young people with RMDs and provide more support to young people to find a suitable job.

In the second version of this workshop the three prioritised objectives were (i) by 2020, there is more awareness in society of the specific needs of young people with RMDs, (ii) health care services are interdisciplinary, more holistic and focused on the need for tailor-made information, including social and psychological support for young people with RMDs and (iii) every European country has an active national youth group for young people with RMDs. The sub-groups considered what steps could be taken to implement activities based on the Young PARE strategy and what EULAR and Young PARE could provide to help.

The three key messages that evolved from the workshops were (i) nothing about the youth without the youth, (ii) empower to create young leaders and (iii) get youth organised.

The voting statements presented during the plenary were:

- By 2020 all PARE member organisations should have a youth group (unanimous agreement)
- The best way to create awareness is to have ambassadors (youth leaders) who talk about their personal experience (majority agreed)

Ingrid Põldema, with the support of Epp Adler and Irene Murphy, ran the second youth workshop on ‘Establishing the young PARE network’. Ingrid provided an overview of the history of the Youth Group and summarised the key findings from the European Youth Survey.

Epp Adler presented a case study on EU Erasmus+ programme in Estonia, mentioning the New EU Education Programme (2014-2020) and examples of funded activities, such as Youth Exchange and Youth Worker Mobility.

Delegates split into sub-groups to develop ideas for (i) an international event and (ii) for leader training, including how to go about funding these activities and how EULAR could help.

The voting statements for this youth workshop were:

- Developing international youth work and using EU Erasmus+ programme is an underused possibility to empower national EULAR PARE members (unanimously agreed)
- There is a need in the EULAR PARE network to increase the knowledge and skills of their national members about the availability of different funding opportunities (unanimously agreed)

Closing the official conference programme

Marios Kouloumas and Diana Skingle presented the conference closing remarks, thanking all delegates for their important contribution to the workshops. Delegates were encouraged to use their workbooks to disseminate what they had learned during the conference to their organisations.

To show support for the World Arthritis Day campaign ‘It’s in your hands, take action’, Marios and Diana invited delegates to turn to their neighbours and give them a ‘High 5’. The campaign involves spreading a gesture that brings two hands together with an uplifting action: the WAD High 5. The aim is to take social media by storm by owning High 5s across Twitter, Facebook, Instagram and all other channels with the hashtag #WADHigh5.

"Interesting topics, useful information and interesting young people!"

Networking and social

With many delegates new to the conference, an icebreaker was held on Thursday evening. This provided a fun way to engage with new people and find out more about their role and organisations, as well as a few light-hearted personal facts. This networking session was well attended and enjoyed.
On Friday evening delegates had the opportunity to participate in a multimedia exhibition. There were 19 posters and 4 videos presented, all of which were inspiring and informative. Delegates were encouraged to take part in the multimedia ‘rally’, challenging them to match each exhibit to a fact about the campaign provided in a list. This encouraged delegates to read the posters, watch the videos and ask the presenters about their campaigns.

Prizes were awarded to the posters from Denmark, for the most successful/innovative campaign around the theme of patient centred care, presented by Julie Kofoed, from Ireland for the most successful/innovative campaign (open theme), presented by John Church and his team, and from Lupus Europe for the most beautiful poster (open theme), presented by Katherine Wheeler. Each of the poster winners was awarded a prize at the gala dinner.

The gala dinner was held at the spectacular and historic Dublin Castle where delegates were treated to an uplifting performance of Irish music followed by a mesmerising display of Irish dancing. The gala dinner included speeches from Marios Kouloumas, Diana Skingle and John Church, who thanked everyone for attending and making the conference such a huge success.

“I have to say that has been one of the best conferences that I have attended - well done and thanks @eular_org and @ArthritisIE! #pare2015”

“We got ideas, tips & contacts. Now make it count! Waiting to see different projects come to life after #pare2015.”

An informal networking session was held for delegates on Sunday morning, giving another great opportunity to share knowledge, experiences and contact details to help them stay in touch!

The next EULAR Annual European Conference of PARE will be held in Sofia, Bulgaria from 15 – 17 April 2016 and hosted by the Bulgarian Organisation for Patients with Rheumatic Diseases (BOPRD).