About the EULAR Annual European Conference of PARE:

Since 1997 a dedicated conference has been held for EULAR member organisations of PARE, which each year is hosted by a different country. The 2016 Conference was held in Sofia, Bulgaria and was hosted by the Bulgarian Organisation for Patients with Rheumatic Diseases (BOPRD).

The overall focus of the conference followed the World Arthritis Day 2015/2016 theme of Patient Centred Care, ‘Taking Control’, with eight workshops on offer, four of which ran twice, allowing delegates the opportunity to attend three different workshops. The workshops covered a range of topics including support for informal carers, online education for PARE, awareness of comorbidities, patient communications, changing perceptions of RMDs, skills training, and two youth workshops.

2016 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 Patient Centred Care, ‘Taking Control’, through:
   - providing expert keynote speakers;
   - sharing best practices;
   - offering skills training.

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 national and local level.

BOPRD objectives:

3. To inform and inspire delegates from BOPRD about EULAR and its activities through participation in the conference.

4. To improve communication between BOPRD and rheumatologists and health professionals in Bulgaria by involving them in the conference.

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

Hans Bijlsma, EULAR President Elect
Boryana Boteva, 2016 Bulgarian Team
Snezhana Bozhinova, 2016 Bulgarian Team
Maarten de Wit, Task Force Member
Marios Kouloumas, EULAR Vice President representing PARE
Elsa Mateus, 2017 Portuguese Team
Christina Opava, EULAR Vice President representing Health Professionals in Rheumatology
Simon Stones, Representative of Young PARE
Dieter Wiek, Chair of the Standing Committee of PARE
Dieter Wiek welcomed delegates and moderated the opening session, which began with the reading of a message of support from Dr Peter Moskov, the Bulgarian Minister for Health. In his opening address, Professor Gerd-Rüdiger Burmester, President of EULAR, welcomed a future in which patients will be involved in their own care and the benefits this will bring in the future. To support the introduction and implementation of shared decision making he announced the launch of the EULAR School of Rheumatology, which he expanded on in his presentation and workshop (2) following the introductory session.

In her welcome address, on behalf of BOPRD, Boryana Boteva, expressed the appreciation of this young organisation for being chosen to host the 2016 conference, and for the support of EULAR and other organisations where doctors and patients collaborate successfully.

Stoyanka Vladeva, a Professor of Rheumatology at the Department of Internal Medicine and Rheumatology Medical Faculty, Trakia University in Stara Zagora, Bulgaria, provided a welcome on behalf of the Bulgarian Society of Rheumatology. She noted that, although Bulgaria faces many economic difficulties, she looks forward to increasing liaison with patient organisations and opportunities for shared decision making, ending her address by saying, “In unity there is strength.”

The welcomes were followed by two keynote presentations. Bozhidar Ivkov, Vice President of BOPRD, and an Associate Professor at the Institute of Sociology at the Bulgarian Academy of Science provided an overview of BOPRD and the situation people with rheumatic and musculoskeletal diseases (RMDs) face in Bulgaria, citing economic problems leading to restrictions on access to treatments and a lack of cooperation with doctors. To address this, BOPRD has run a series of high profile and imaginative campaigns drawing attention to the challenges faced by people with RMDs, and emphasising the need for a greater dialogue with the Ministry of Health.

Gerd-Rüdiger Burmester expanded on the patient centred care model and described the importance of not only ‘treating to target’ but, by extension, ‘treating to participation’, where the patient is involved in shared decision making, as practised in Germany. He also explained how the model could enhance outcomes.

He expanded further on the EULAR School of Rheumatology and how this exciting new initiative for PARE will provide a place to develop decision aids to enhance communications between patients, doctors and the wider population.

Streaming and Twitter engagement

Plenary sessions and selected workshops were live streamed in English and Bulgarian. The stream can now be viewed on YouTube and on the EULAR website. Delegates and the external audience once again were able to engage with the conference via Twitter. Twitter engagement was high; with more than 1,538 Twitter mentions from 182 users including #pare2016, reaching a potential audience of 1.9 million people.

[TWEET] “Tell the patients their options. This is key to take decisions said EULAR President #PARE2016”
people with RMDs, their healthcare teams, peers, family and friends. Other educational tools will also be developed in the future.

“The Conference was absolutely fantastic. It was very empowering to me as a patient and I am now able to share the lessons learned on a national and European level. Thank you.”

Panel discussion
Following the opening addresses the panel agreed on the importance of increasing opportunities for shared decision making, individual tailored care and involving a multidisciplinary team that would also include health professionals screening for comorbidities. However, it was noted that inequalities exist across Europe, with countries like Bulgaria still having little to no knowledge or understanding of the concept of the partnerships between patients and health professionals that are necessary to achieving patient centred care.

**Best Practice Fair**

This year, for the first time, a Best Practice Fair was introduced on Friday afternoon, with delegates encouraged to bring posters and videos depicting campaigns or activities undertaken by their organisations over the past year. The posters were grouped into three separate categories, based on the audience they were targeting: (i) people with RMDs; (ii) the public; and (iii) policy makers.

Winners for each category were awarded a small prize and invited to present and discuss their campaign or activity at the Best Practice Panel Discussion.

The winner for the category aimed at people with RMDs was Youth-R-Well.com for their ‘Guide to Establishing an Online Youth Platform’. As a successful youth group, Youth-R-Well.com hoped to use their guide to disseminate their experiences and help other organisations in establishing an online youth platform.

The winner for the category aimed at the public was the Hellenic League Against Rheumatism, which produced a video to raise public awareness of chronic diseases and to highlight ‘The Rights of Patients with RMDs in Greece’.

The winner for the category aimed at policy makers was Arthritis Ireland, for their successful pre-election campaign ‘Why are we Waiting?’ that asked the new government to support the needs of people with RMDs in Ireland and for politicians to identify themselves as an ‘Arthritis Champion’.

**Workshops, feedback and voting statements**

Interactive feedback sessions were held following the workshops on Friday and Saturday. Workshop leaders presented their feedback using a number of statements related 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), red (disagree) or white (unsure) voting cards. It should be noted that the statements developed in the workshops were designed to provoke discussion and debate and did not in any way represent the views of EULAR.

**John Church** moderated the informal, interactive workshop feedback session with voting following the Friday workshops. A similar session was held on Saturday, moderated by **Professor Christina Opava**.

“The Best Practice Fair was an amazing experience. I believe it gives organisations the opportunity to share their work and help other organisations with ideas and best practices. It also gives organisations the chance to be creative and connect!”
Friday workshops

Workshop 1: Campaigning for support for informal carers

Marios Kouloumas facilitated a campaigning workshop to acknowledge and support the role of informal carers for people with RMDs, based around a case study given by Dr Giovanni Lamura, a social gerontologist working at the Italian National Institute of Health and Science on Ageing and working with Eurocarers, the European Association Working for Carers. The workshop began with an overview of the specific needs of people with RMDs and their informal carers. Interactive discussions included the role of informal carers, the nature of support currently provided for them and where carer support should be focused in the future.

"An excellent three days to meet and learn from like-minded people. I was particularly impressed with the younger delegates and what they have achieved."

In his presentation, Giovanni Lamura, showed the current provisions for carers in Europe, including provisions for different aspects of support and provided an overview of the status of carers, including the economic value of informal care.

With support from Giovanni Lamura and Christina Opava, delegates formed into three sub-groups to discuss selected campaigns or activities that organisations could develop to support informal care for people with RMDs, with a focus on the specific type of support needed for informal carers. The groups brainstormed elements for campaigns and activities that could be developed by national organisations. Delegates’ suggestions included introducing an Informal Carers Week and more support groups for informal carers.

Three statements were voted on in the feedback session:

- All patient organisations should provide education, psychological and peer support to informal carers
  - Delegates generally disagreed and suggested this should be handled by other stakeholders
- Carers should take time for themselves (no matter what)
  - The majority of delegates agreed
- All financial support for carers’ needs should come from the State
  - The majority of delegates agreed, although there were some mixed opinions

Workshop 2: EULAR online educational tool

Gerd-Rüdiger Burmester, with the support of Dieter Wiek and Nele Caeyers, a member of the PARE Board, presented the new EULAR online educational tool and the opportunities that this presented for PARE. Gerd-Rüdiger Burmester began by sharing the outcomes of discussions with a PARE taskforce on how best to utilise this platform for the benefit of the patients and provided an overview of the topics that will be covered by the EULAR online educational tool.

Each of the three subgroups focused on a specific educational topic, and brainstormed the specific skills and knowledge they would like to acquire. The topics discussed were: (i) General skills for volunteers; (ii) Capacity building; and (iii) Medical information.

Within their assigned topics, all groups brainstormed the best format to acquire the desired skills, and ways in which the challenges of online learning could be overcome. Delegates’ suggestions included using simple English and the possibility of introducing tests and accreditations.

Three statements were voted on in the feedback session:

- Volunteer work must be professionalised
  - The majority of delegates agreed, although responses were mixed
- Medical information must be approached positively, be understandable, and be available on the internet
  - All agreed
- EULAR should be teaching organisations to use social media effectively
  - Nearly all delegates agreed, although some felt that this was not a task for EULAR
Workshop 3: Comorbidity screening in patients

Dr Yvonne van Eijk-Hustings, a rheumatology nurse at the Maastricht University Medical Centre, The Netherlands, with the support of Dr Maarten de Wit and Nikola Kirilov, a third year medical student at Trakia University, Bulgaria, ran a workshop on increasing awareness of screening for co-morbidities among people with RMDs. This workshop was live streamed and run in both English and Bulgarian. To begin, Yvonne van Eijk-Hustings provided an overview of co-morbidities and of a new screening and reporting tool, with all delegates having been provided with a sample co-morbidity checklist. Maarten de Wit introduced the PARE guide for the dissemination of EULAR recommendations to patients, focusing on how to make the recommendations as accessible and applicable as possible.

Three subgroups, discussed how the checklist could be better understood by patients, the kind of educational materials needed by patients to become involved in the screening of comorbidities and the ways in which the screening and reporting tool could best be integrated into healthcare. One of the subgroups was exclusively for Bulgarian delegates, and was overseen by Nikola Kirilov. Amongst other suggestions, delegates emphasised the importance of using simple terminology, the benefits of developing an app and utilising preventative activities.

Three statements were voted on in the feedback session:
- Patients do have the right not to know their risk of comorbidities
  - There was a mixed response to this statement
  - In my country health professionals are not interested in screening for comorbidities
  - There was a mixed response to this statement, with delegates from some countries such as The Netherlands stating there was interest, and others like those from Bulgaria saying that there was no support
- Specialized nurses should support patients in the screening and reporting of comorbidities
  - The majority of delegates agreed

Workshop 4: Building the Young PARE network

The first youth workshop, run by Simon Stones with support from Linda van Nieuwkoop, past chair of Youth-R-Well.com and continuing professional supporter of the project, focused on Young PARE. They introduced the Young PARE Virtual Knowledge Centre and explored the best ways to set up a group for young people within a EULAR national member organisation of PARE. The workshop began with an interactive discussion on the key challenges of setting up a youth group which identified a lack of skills and relevant experience, and the struggle to engage with and retain young people with RMDs.

Silvia Ostuzzi, staff member of ALOMAR, the Lombardy regional association for people with RMDs in Italy, described the successful set up of the newly formed ANMAR Young with support from the Netherlands Youth-R-Well.com and the EULAR Knowledge Exchange Program. Having identified and prioritised barriers to setting up a youth group, the three subgroups brainstormed ideas to overcome these barriers and developed a list of tips and considerations for success. Many of the solutions centred on online outreach and the need for increased awareness of RMDs in the general population. Delegates also emphasised the importance of mentorship in gaining the skills required for setting up an online group.

Two statements were voted on in the feedback session:
- A youth group can be started, and sustained, by the youth only. Age is just a number – it’s all about personality
  - Most delegates agreed with this statement, although there was some disagreement
- Disclosure is a bigger problem for children and young adults, than it is for ‘older people’ with RMDs
  - Most delegates agreed with this statement, although there was some mixed response
Saturday workshops

All Saturday workshops were repeated twice, allowing delegates to attend two different workshops.

“I liked the structure of the programme and the fact that the second day was mostly spent on workshops. It was great and kept all the delegates actively participating throughout the conference.”

Workshop 5: Making RMDs sexy – how to change perceptions of RMDs

John Church, CEO of Arthritis Ireland, with the support of Marios Kouloumas and Diana Skingle, Past Chair EULAR SCoPARE, ran a workshop on changing perceptions of RMDs. To begin the workshop, delegates identified what they felt to be the largest misconceptions about RMDs and categorised them into three main groups. In his case study, John Church, showed some of the inspiring campaigns developed and implemented by Arthritis Ireland to try and change perceptions of RMDs, including showing two videos focusing on young people with RMDs.

The three sub-groups discussed the types of activities that could be developed to change perceptions, the audience that most needed to be engaged, and what messages and communications channels could be used to change perceptions. Delegates emphasised the need for respect, not pity and of focusing on a person centred approach, as opposed to a patient centred one.

Three statements were voted on in the feedback session:

• The way to change perceptions of RMDs is to use imagery of children and young people
  o Most delegates were in agreement, although some were wary of misusing images of children
• The word ‘Arthritis’ is no longer useful in raising public awareness about RMDs
  o There was mixed reaction to this statement, with most delegates expressing that they understood the underlying message, but needed a new phrase
• Everybody can do something, nobody can do everything
  o All delegates agreed

[TWEET] “Stigma that arthritis is an old person’s disease, and that young people are ‘patients’ still very much in existence #PARE2016”

Workshop 6: Young PARE; facilitating transition from child to adult in young people with RMDs

The second youth workshop focused on facilitating transition from child to adult in young people with RMDs. The workshop was led by Dr Judy Ammerlaan, a nurse researcher at the Department of Rheumatology and Clinical Immunology, University Medical Centre Utrecht, The Netherlands, with support from Lucy Gossens, a clinical nurse specialist and transition coordinator at the same medical centre, and Simon Stones. One of the workshops was live streamed and available in Bulgarian.

Judy Ammerlaan noted that from the pre-conference questionnaire it was evident that whilst few organisations currently had activities specifically targeting young people, most were interested in developing them. Lucy Gossens, a transition coordinator at UMC Utrecht, provided a case study of the way in which...
transition is handled at her place of work, and of the best practices in facilitating transition.

The three subgroups each focused on a specific recommendation to facilitate transition from youth to adult: (i) Start early, the transition process should begin as soon as possible; (ii) Know the rules, there should be a clear written description of the multidisciplinary team involved; and (iii) Person-centred, transition services should be focused on young people and address the complexities involved. Delegates emphasised the importance of family in transitioning and that there should be increased emphasis on peer-to-peer support, amongst other ideas.

Two statements were voted on in the feedback session:

- Transition from child to adult is the time when people with RMDs need the most support
  - There was general agreement to this statement

- Patient organisations should be able to better support parents and carers as their son or daughter transitions between child and adult services
  - There was mixed response to this statement, with some of the younger delegates emphasising that most importance should be focused on the person in transition

Workshop 7: Improving communications between patients and their healthcare team

This workshop, led by Dr Rieke Alten, Head of the Department of Internal Medicine, Rheumatology, Clinical Immunology and Osteology at Charité Hospital, Berlin, with support from Dieter Wiek and Nikola Kirilov, looked at ways of improving communications between patients and their healthcare teams. This workshop was live streamed and with a Bulgarian subgroup being moderated by Nikola Kirilov, who also took the part of a doctor in a role play to demonstrate examples of poor communication practice between a doctor and patient (played by Boryana Boteva).

Rieke Alten gave a presentation on the characteristics, tools and recommendations for improving communications between patients and healthcare professionals, emphasising patient centred care.

Peter Bühm provided a case study on a project to help improve communications between people with RMDs their healthcare team and others. The project has been developed by the University of Halle-Wittenberg and the University of Freiburg with research partner, the Deutsche Rheuma-Liga (DR-L). The model is currently being piloted and includes an evaluation on the effectiveness of the model. Implementation of the communication training will be conducted through Deutsche Rheuma-Liga self-management groups.

Two of the three subgroups discussed ways to help patients communicate better with their healthcare teams and the other group discussed ways in which healthcare teams could communicate better with their patients. Delegates stated the importance of patients being prepared, having family support and overcoming language barriers and of healthcare professionals using easy to understand language, having specific consultations and directing patients to networks and support groups.

Three statements were voted on in the feedback session:

- Empowering patients and healthcare professionals (HCPs) is a necessary process to practise shared decision making
  - All delegates agreed

- Patients and HCPs have to learn to speak the same language and to be partners on an equal level
  - Delegates were generally in agreement

- Patient organisations should encourage HCPs and their organisations to practise shared decision making
  - There was general agreement for this statement, although many delegates expressed that this cannot be a one-way street, HCPs should want to practice shared decision making
Workshop 8: Skills training and presentation skills

Epp Adler and Esmé Newton-Dunn each ran a practical presentation skills training workshop with Epp Adler focusing on building the confidence of delegates with less presenting experience and Esmé Newton-Dunn focusing on providing practice and tips for those with more experience.

Two statements were voted on in the feedback session:

- There is one perfect way of making presentations that always works and suits everybody in giving a successful presentation.
  - All delegates disagreed
- A good presentation is more about the person presenting than about the content.
  - There was a mixed response to this statement.

“I attended three workshops, which for me was a very positive experience. My colleague talked about the other workshops and I felt as if I had done them all!”

Closing the official conference programme

Marios Kouloumas and Dieter Wiek provided the conference closing remarks noting that organisations for people with RMDs need knowledge and education to become more empowered, highlighting the inspiring examples of achievements featured in the Best Practice Fair. They also noted the importance of changing perceptions of RMDs and the leading role that young people with RMDs and EULAR Young PARE can take in helping to achieve this now and in the future.

From the perspective of BPORD Marios and Dieter hoped that the conference and support from EULAR would help improve interaction with their different stakeholders and the provision of healthcare for people with RMDs.

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 by all.

On Sunday morning an informal networking session was held for delegates providing another opportunity to share knowledge, experiences, and contact details for continued liaison.

[TWEET] “Bye bye #PARE2016! Welcome #PARE2017! Keep up the hard work for all 120mill suffering from RMDs!”

The gala dinner was held at the Chevermeto Restaurant, where delegates were treated to traditional Bulgarian food and drink, as well as an energetic performance of Bulgarian music and dancing, with many delegates joining in.

The next EULAR Annual European Conference of PARE will take place on 24th – 26th of February 2017 in Lisbon, Portugal.