

Biennial report

Study Groups

EULAR Study Group on Patient Education (STOPE)

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Aims of STOPE

EULAR Study group on Patient Education (STOPE) is formed of 41 multinational health professionals, rheumatologists and patients interested in patient education within rheumatic and musculoskeletal health care. STOPE was established in September 2015 with the following overarching aims: (i) to promote excellence in patient education research (ii) to disseminate research evidence (iii) to support implementation of EULAR recommendations that have a patient education approach and (iv) to promote collaboration among professionals and patients interested in patient education across Europe.

Summary of last year's activities

The first group meeting

The group members met for the first time at EULAR Congress 2016 in London. The meeting was attended by 15 members and 13 apologies were received. There were 10 countries represented at the meeting: France, Hong Kong, Ireland, India, Japan, Netherlands, Portugal, Spain, Switzerland and the UK. This meeting aimed at introducing the study group's aims and objectives, set priorities, discuss the strategy and identifying national champions who would carry out the agreed action points.

This group had applied for a EULAR HP research grant in 2016 for a dissemination and evaluation project but this was unsuccessful. Since the dissemination work was not funded, it was agreed that STOPE should make the translation and dissemination a priority, and country champions should find support from their own institutions or within-country organisations.

The country champions were identified and the priority was to start the work of translating patient education recommendations aimed for professionals. The translation focus was set on the two overarching principles and the 8 recommendations specified by Zangi et al (2015) but not the whole article. The Lay version of the recommendation was not complete at this stage, therefore it was decided to wait until the recommendations for professionals are complete. The minutes of this the meeting were circulated to all group members by email.

Work carried out to-date

Since the meeting in June 2016, the translation of the recommendations for health professionals has been undertaken in the following countries: Denmark, France, Norway, Portugal, Sweden, Switzerland, Spain and The Netherlands. Work was planned in India, but it was later found that English is the medium of professional communication in India therefore only the lay version needed translating into Hindi.

To date, we have the recommendations for professionals in the following languages: French, German – for Germany, German for Switzerland, Spanish and Swedish. The translation process involves a panel consensus approach and this process is still ongoing in the following countries: Denmark, Netherlands, Norway and Portugal. In these countries, some members of the panels have undertaken the translation but consensus meetings have not taken place yet.

The next priority was to disseminate the recommendations. Two countries (German and Sweden) have published articles in peer reviewed journals (Boström, 2016; Patermann, 2016) and others have submitted the recommendations to their national organisations. However, the work of dissemination is ongoing and the group is working on a survey items aimed at disseminating the recommendations and assessing their acceptability and applicability among professionals.

In 2015, EULAR commissioned PARE to develop lay summaries for all EULAR recommendations. The lay summary of the patient education recommendations was completed and published in September 2016 (PARE, 2016). STOPE was invited to review the lay version before being finalised.

Ongoing and future work

The lay summary (PARE, 2016) will be translated into different languages in order to enhance further dissemination to patients with inflammatory arthritis across Europe and beyond. STOPE will continue to coordinate the translation work but country champions will take the lead and work closely with patient organisation in their respective countries.

At Madrid EULAR Congress, STOPE will meet on the 16th June 2017 in room S15 at 1700-1800 hrs. Dr Heidi Zangi (STOPE's co-lead) will chair the meeting, which will evaluate the group's activity and set the priorities for the next year. STOPE follows an open membership policy and seeks to extend membership to all EULAR countries. New membership applications should be sent to Dr Mwidimi Ndosi mwidimi.ndosi@uwe.ac.uk or Dr Heidi Zangi heidi.zangi@diakonsyk.no.

References

1. Zangi HA, Ndosi M, Adams J, et al. EULAR recommendations for patient education for people with inflammatory arthritis. *Ann Rheum Dis* 2015;74(6):954-62. <http://dx.doi.org/10.1136/annrheumdis-2014-206807>
2. Boström AC. EULAR-rekommendationer för patientutbildning vid inflammatorisk artrit. *BestPractice Reumatologi* 2016; <https://bestprac.se/2016/07/25/eular-rekommendationer-for-patientutbildning-vid-inflammatorisk-artrit/>
3. Patermann J, Ehlebracht-König I, Lind-Albrecht G, et al. [EULAR recommendations for patient education of people with inflammatory arthritis. Translation and evaluation in Germany]. *Z Rheumatol* 2016;75(2):187-99. <http://dx.doi.org/10.1007/s00393-015-0020-z>
4. PARE. Education for people with inflammatory arthritis: BMJ Publishing Group Ltd & European League Against Rheumatism; 2019 [updated 12 Sep. Available from: <http://promotions.bmj.com/ardsummaries/2016/09/12/education-for-people-with-inflammatory-arthritis/>

The current membership

Name	Profession (Country)	Name	Profession (Country)
1. Mwidimi Ndosi (Lead)	Nurse (GB)	22. Kjersti Grønning	Nurse (NO)
2. Heidi Zangi (Co-lead)	Nurse (NO)	23. Laure Gossec	Rheumatologist (FR)
3. Agnes Kocher (CC)	Nurse (CH)	24. Lena Andersen	Patient (DK)
4. Alison Hammond	Occ Therapist (GB)	25. Manly Tang	Nurse (HK)
5. Andrea Marques	Nurse (PT)	26. Marieke Scholte	Patient (NL)
6. Astrid van Tubergen	Rheumatologist (NL)	27. Marja Leena Kukkurainen (CC)	Nurse (FI)
7. Bente Hamnes	Nurse (NO)	28. Masa Huzjak	Nurse (SI)
8. Carina Boström (CC)	Physiotherapist (SE)	29. Matylda Sierakowska (CC)	Nurse (PL)
9. Christina Bode	Psychologist (NL)	30. Mie Fusama (CC)	Nurse (JP)
10. Cristina Hernandez	Patient (ES)	31. Patricia Minnock (CC)	Nurse (IE)
11. Françoise Fayet (CC)	Nurse (FR)	32. Michaela Stoffer	Occ Therapist (AT)
12. Gabriel Mendes	Patient (PT)	33. Roopa Rawat (CC)	Nurse (IN)
13. Gladys Kwok (CC)	Nurse (HK)	34. Ricardo Ferreira (CC)	Nurse (PT)
14. Hideko Nakahara	Nurse (JP)	35. Sarah Ryan	Nurse (GB)
15. Ingrid Larsson	Nurse (SE)	36. Silvia Garcia-Diaz (CC)	Nurse (ES)
16. Jana Korandová (CC)	Nurse (CZ)	37. Sue Oliver	Nurse (GB)
17. Jenny de la Torre (CC)	Nurse (ES)	38. Tiziana Nava	Physiotherapist (IT)
18. Jette Primdahl (CC)	Nurse (DK)	39. Ulrika Bergsten	Nurse (SE)
19. Jo Adams	Occ Therapist (GB)	40. Yeliz Prior	Occ Therapist (GB)
20. Jorit Meesters	Physiotherapist (NL)	41. Yvonne van Eijk-Hustings (CC)	Nurse (NL)
21. Karin Niedermann	Physiotherapist (CH)		

CC, Country Champion