

**Objectives:**

- Mapping beliefs of researchers and PRs about the potential value of patient involvement in basic research.
- To document experiences of both patient representatives and researchers of a pilot project of PRs participating in basic research.

**Methods:** The method of participatory action research has been used. This is a research approach that emphasizes both participation and action [2]. In this case two working groups were involved. The coordinator participated in meetings of the working groups, made notes during these meetings about the nature and degree of participation, evaluated the meetings with the participants and kept a diary. At the start and at the end of the pilot 6 researchers of the working groups were interviewed by the coordinator. The findings of the interviews were categorized and summarized. During 6 months, 5 PRs were invited to attend once a month, in one of the working group meetings. In the first meeting expectations of both researchers and PRs were exchanged. In the following meetings one researcher presented a lay version summary of his/her work. There was room for PRs to ask questions.

**Results:** Prior to the pilot, some researchers had doubts about the added value of PRs, others were more positive and even curious. All PRs were open minded about the pilot, although none of them had experience with involvement in basic research.

At the end of the pilot, researchers expressed positive statements, such as: "(very) nice, good initiative and interesting discussions." Positive experiences included: exercise in explaining their work to lay persons; stimulation in developing a more holistic (helicopter) view of their research, and getting a better insight in problems in daily life that patients encounter.

The PRs experienced the atmosphere during meetings as open and pleasant; they felt that the degree of participation was limited, but worthwhile.

The coordinator observed that interaction between the researchers and PRs mainly consisted of asking questions for clarification. Besides, the coordinator observed after presentations exchanges between PRs and about research-related issues such as the availability of human tissues for research and conversations about personal experiences.

Critical comments were made about the difficulty in understanding the complex matter for PRs and the chosen method (researcher presents, PRs listened) that does not encourage interaction.

**Conclusions:** There is a potential value of patient involvement in basic research. A first result is that junior researchers develop a more holistic view of their research subject.

An open atmosphere and low expectations may contribute to success. Continuation of this pilot with modifications, including more research groups and PRs, are needed to find ways to increase patient involvement in basic research.

**References:**

- [1] Hsiao B., Fraenkel L., Incorporating the patient's perspective in outcomes research. *Wolters Kluwer Health* 2017 Number 00, volume 29.  
 [2] Wikipedia. [https://en.wikipedia.org/wiki/Participatory\\_action\\_research](https://en.wikipedia.org/wiki/Participatory_action_research).

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### PARE0007 HOPES AND FEARS OF PATIENTS WITH AXIAL SPONDYLOARTHRITIS IN SPAIN. THE VALUE OF PATIENT OPINION: RESULTS FROM THE SPANISH ATLAS

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**Background:** Not much attention has been paid to listening to the opinions of patients in most scientific studies on Spondyloarthritis, despite their opinions playing an increasingly important role in decision-making alongside clinical and public health criteria.

**Objectives:** To assess the opinions of patients with Axial Spondyloarthritis (ax-SpA) using qualitative information.

**Methods:** A sample of 680 patients diagnosed with ax-SpA was interviewed during 2016 as part of the Spanish Atlas, which aims to promote early referral and improve healthcare and the use of effective treatments in patients with ax-SpA. The Atlas is a CEADE initiative (Spanish Coordinator of Patients with ax-SpA in Spain) developed by the University of Seville and Max Weber Institute in collaboration with GRESSER (Spanish Rheumatology Society spondyloarthritis study group). Responses to qualitative items about patients' hopes and fears for their disease and their personal aims regarding their treatment were analysed.

**Results:** 53% were females, mean age 46 years and 77.1% were HLA-B27+. The five main hopes of patients are: stopping the disease, dream of a cure, elimination of pain, improve their quality of life and live without limitations. Additionally, patients have expectations on the medical research outcomes. Thus, 81% of patients hope that the research will make possible to find the cause and a cure for ax-SpA, developing more efficient biologic therapies (11%), and finding new techniques or medication (8%).

The following stand out among drug treatment-related concerns: having more effective treatments (32%), sustaining the results of biologic therapies (29%), being able to start on biologics (8%), the public health system funding non-drug treatments for AS (8%), eliminating secondary effects (15%), reducing prices (4%), and correct use (4%).

With respect to their fears, patients stated that their main concern was mobility loss (31%), followed by loss of independence (23%), disability (22%), stiffness (12%), structural damage (3%), organ damage (3%), other illnesses and diseases related (3%), physical decline (3%), and sight loss (1%).

Patients who expressed fear regarding their disease listed their greatest concern was that they would not overcome or tolerate pain (56%), followed by the fear that the disease would develop (32%), along with apprehension about flare-ups (7%), and tiredness (5%).

With respect to patients' personal objectives in terms of their treatments, they highlighted the wish that their treatment would, first, help them to reduce and eliminate pain, increasing their in mobility, improved quality of life, the avoidance of structural damage and the disease eventually being cured.

**Conclusions:** Analysis of patient opinion using qualitative information has enabled the identification of important concerns for patients such as discovering the cause of the disease, reducing pain and structural damage, loss of self-sufficiency and disability.

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THURSDAY, 15 JUNE TO SATURDAY, 17 JUNE 2017

### Best practice campaigning

#### PARE0008 TRANSITION: PARTICULARLY DIFFICULT TIME FOR YOUNG PEOPLE WITH AR

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**Background:** Transition is a multifaceted process involving medical, psychosocial, educational needs of the teenager who must move from a pediatric care to adult care system.

The pediatric paradigm focuses on the family, it focuses on aspects of growth and development, often neglecting, to acknowledge the increasing independence and autonomy of the patient as an individual.

The culture of adult medicine implies to have as a partner a patient independent and autonomous in the management of the disease, including aspects of playing, ignoring the issues related to the growth, development and relations with the family.

**Objectives:** to drive the patient along the transition, getting him finding the new treating as a continued assistance, more mature and personalized in sharing issues related to the disease; to create a best practice of transition service.

**Methods:** promoted by AMaR Piemonte - regional expression of ANMAR - and thanks to the availability and sensitivity of the doctors of the Pediatric Rheumatology Service (responsible Prof. Silvana Martino) and the UOA Rheumatology (director dr. Enrico Fusaro), located in two different buildings of the same "Città della Salute e della Scienza di Torino" hospital, it was possible to organize a transition pathway for teenagers since eighteen, structured as follows:

- first telephone contact between Pediatrician Rheumatologist and Rheumatologist
- sharing of clinical and personal information about the young patient
- introduction to the new care giver: during the routine consultation Pediatrician Rheumatologist presents his colleague, anticipating the different types of examinations and departmental activities and highlighting the peculiarities and sensitivity of his colleague
- meeting with parents: on the fringes the two specialists meet parents, preparing them for their future role and announcing that in the next visit they will be excluded
- transition examination: directly scheduled, it is a joint examination by the two rheumatologists to the young patient, who is directly involved discussing his health state and the decisions to be taken to continue therapies or monitoring the disease (if in remission). A second one may be scheduled if the young patient shows severe psychological problems.

A collegial meeting between patient, rheumatologists and physiatrist/rehabilitator will be programmed if a special rehabilitation is needed

- taking care: the new rheumatologist takes care of the young patient

All the pathway takes end in a period of time not exceeding one month, with a maximum of three consultations.

**Results:** 52 patients (79% female, 21% male) taken in care by "adult" rheumatology since 2012 to 2016. No patient reports he lived the transition as a trauma and 10%, even saying to have found in the new rheumatologist a sure and affordable referral, stay in contact with the pediatric rheumatologist "because of emotional issues". 58% remains under treatment with DMARDs and biologics; in 32% of patients an extra-articular manifestation occurs even in the absence of clinical parameters indicative of medium-high disease activity. The remaining 10%, in remission, continues the control.

**Conclusions:** Transition is an educational and therapeutic process, not an event; it requires collaboration between the teenager, family and caregivers.

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