Facilitators of patient involvement related to a) education of principles of participatory research; b) training of patient-researcher collaboration; c) development of a common language level; d) open mind and respectful communication; e) professional support; and f) leadership commitment. Main barriers were the complexity of pathogenetic processes for patients and time commitment for researchers. All participants found the collaboration worthwhile.

Reported impact was divers. Having to look at their work from a helicopter view encouraged researchers to attain a holistic view of people with a rheumatic condition and skills to explain their research for a lay audience. Patients experienced personal satisfaction after sharing experiences and receiving recognition from others. For the research process, a few examples were reported where patients input led to new topics on the research agenda. One example was the grant application to explore determinants of fatigue in the laboratory, directly prompted by patients. More substantial benefits were experienced for the development of patient friendly educational materials and lay summaries of research protocols, dissemination of research findings through interviews and presentations, and even promotion of patient participation in national scientific societies of which the researchers are a member. Little impact was reported on the actual results of basic research.

Conclusion: Long term patient involvement in basic research is feasible and worthwhile. Despite the time investment, both patients and researchers experience valuable benefits that outweigh the lack of tangible impact on research findings.

Disclosure of Interests: None declared

DOI: 10.1136/annrheumdis-2019-eular.4543

AB1350

HOW TO REDUCE THE NOCEBO EFFECT IN RHEUMATOLOGY? A SYSTEMATIC REVIEW OF RISK FACTORS AND INTERVENTION STRATEGIES

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Background: Nocebo effect (NE) defines any declared negative side effect of a drug that is non-specific, non-explained by its pharmacokinetic, and non-dose dependant. Recently, it has been pointed out as the main factor that reduces the retention rate of switches from a biologic originator (BO) to biosimilars (BS) in rheumatology.

Objectives: To identify the risk factors (RFs) and interventions strategies to reduce the NE in rheumatism and musculoskeletal diseases (RMDs), and more specifically in BS switches.

Methods: MEDLINE, Embase and Cochrane databases were systematically searched (inception to 15th November 2018) using relevant keywords: search1: "musculoskeletal diseases" and "nocebo" or "non-specific side effect" (NS-SE); search2: "biosimilars" and "nocebo" or "non-specific side effect". Inclusion criteria were: studies on pharmacological treatments, studies investigating RFs for NE or NS-SEs, studies specifically describing an intervention aimed to reduce NE. Studies on non-RMDs and fibromyalgia were excluded.

Results: Of 212 and 639 references screened respectively in search1 and search2, 151 duplications were deleted, 32 mentioning NE or equivalent were read in full text by 2 independent investigators and consensually selected.

No study met inclusion criteria for NE risk factors: 6 studies investigated the RFs of discontinuation after switch to BS, 3 with etanercept (ETN), 3 with infliximab (IFX), one investigated risk factors of back switch (meaning return from BS ETN to BO ETN), one study analyzed a genetic factor of intolerance to methotrexate (MTX) in juvenile idiopathic arthritis (JIA) and one study assessed the RFs for overall discontinuation of biologics. Although contextual factors were mentioned, no study tested RFs on NE responders only. RFs for a negative outcome were low self-efficacy, small-size rheumatology department, early start of IFX BS after its introduction on the market.

Only 5 studies met the inclusion criteria for specific interventions to reduce NE. One was about countermeasures used to reduce MTX intolerance in children with JIA: including covert dosing and taste masking, with no significant results. The other four studies aimed to reduce NE related to a switch: by a shared decision-making method (ETN, one study), another by a structured communication strategy (ETN, one study) and two by a standardized information (ETN, one study; IFX, one study). Rate of NS-SE was mentioned in 3 studies, and the outcome (NS-SE rate compared to NE-SE rate of control group) was mentioned in only 2 studies. However, the assessment of intervention efficacy was not possible, since comparison was performed with historical cohorts.

Conclusion: Although nocebo effect is an important issue in rheumatology, especially as an explicative factor for limiting the retention rate when switching from biologic originators to biosimilars, its risk factors and intervention strategies to prevent it are poorly known. Our results encourage studies to better understand the risk factors associated with nocebo effect and the means to reduce it, particularly in the context of switches from bio-originators to biosimilars.

Disclosure of Interests: None declared

DOI: 10.1136/annrheumdis-2019-eular.3775

AB1351

DO WE NEED A PATIENT PEER MENTOR PROGRAM IN DAILY PRACTICE FOR PATIENTS WITH EARLY RHEUMATOID ARTHRITIS AND IF SO, HOW SHOULD THIS BE ORGANIZED?

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Background: Management and support by an interdisciplinary rheumatology team are essential for achieving optimal disease outcomes in rheumatoid arthritis (RA). Nevertheless, health professionals generally do not experience the disease themselves, and patients may have specific educational needs that can only be provided by other patients having gone through the same experience. Furthermore, patients with RA may benefit most from such additional care interventions in the early disease stage when they are particularly faced with threats to their normal life. Peer mentoring has been studied and successfully implemented in other chronic conditions, however, this is rather a new care concept in the field of rheumatology.

Objectives: Among four key stakeholders in the management of early RA, we aimed (1) to uncover the current experience with, need for and attitude towards implementing peer mentoring in the care for patients with early RA in Flanders; (2) to gather ideas for the content and format of a peer mentor program.

Methods: We conducted an explorative qualitative focus group study. In total, five focus groups were organized to capture the perspective of each of the following stakeholders: patients with early RA (n=10), representatives of patient organizations (n=5), rheumatologists (n=10) and rheumatology nurses (n=5). Data were analyzed using the constant comparison method as presented in the Qualitative Analysis Guide of Leuven. Two patient research partners helped to analyze and interpret the data.

Results: Most stakeholders perceived a potential need for peer mentoring in early RA. However, they underscored that this would be largely person and disease phase dependent suggesting that peer mentoring should be presented as an option to patients, rather than a standard of care. The additional value of peer mentors would be foremost situated in providing disease perspective and a sense of recognition to newly diagnosed patients. For some stakeholders, it was difficult to get a clear picture of such a program, which made it difficult for them to formulate an opinion on a specific format. The health professionals particularly mentioned the current lack of a formal framework for collaborating with patient experts, and the need for carefully selected and well-trained peer mentors. Stakeholders shared the view that the development of a peer mentor program and its integration within the current care context should ideally take place in co-operation with and under supervision of health professionals.

Conclusion: Our results underline that peer mentoring in early RA holds potential for certain patients under certain circumstances, yet a clear framework for all stakeholders is a prerequisite to ensure a chance for success of this complex intervention. Future research should thus focus on unfolding the facilitators and barriers of collaborating with patient experts in the daily care of patients with early rheumatoid arthritis.

Acknowledgement: This work was supported by Fonds Wetenschappelijk Reuma Onderzoek (FWRO).

Disclosure of Interests: Kristien Van der Elst: None declared, Lore Bangels: None declared, Lianne Peerlings: None declared, Lies De Caluwé: None declared, Ilse Langers: None declared, Veerle Stouten: None declared, Diederik De Cock: None declared, Rene Westhovens Grant/research support from: Bristol-Myers Squibb, Consultant for: Celltrion, Galapagos-Gilead, Patrick Verschueren Grant/research support from: Unrestricted Pfizer Grant for Early RA research

DOI: 10.1136/annrheumdis-2019-eular.6765