

Patient Champions in JIGSAW-E

Maartin de Wit, Netherlands

How did you get involved in JIGSAW-E?

In the past I have collaborated several times with the Keele team to discuss the challenges of patient participation in health research. From the very first moment, I was impressed with the enthusiasm, dedication and professional attitude of building and empowering the Research User Group.

I don't have osteoarthritis but as a person with psoriatic arthritis, and as coordinator of the EULAR network of patient research partners, I knew that I could learn a lot from the experiences of the Keele team. It was therefore that I didn't hesitate to say 'yes' when they asked me to become a member of the international advisory group for the JIGSAW-E project.

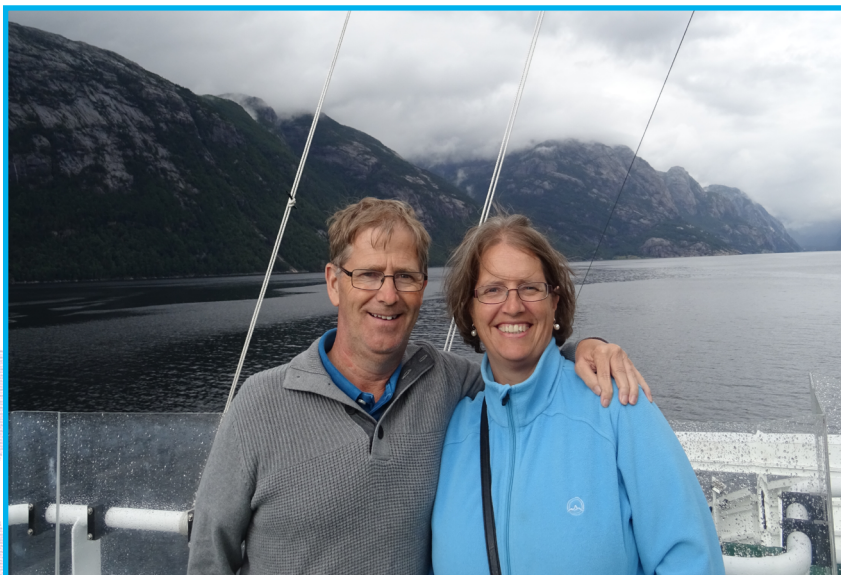


The Keele team stands for meaningful participation of patients in all the work that they do and the intention to learn from the experiences of all involved. For me it was an honor to be part of that endeavor. I attended the first JIGSAW-E meeting in Keele in 2016 and till now I have not been disappointed.

What is your role as Patient Champion?

I participate in the international advisory group, contributing to the planning of follow-up activities and make sure that patients are involved in all the different implementation activities. One of the desires of the patient champion group was to have a face-to-face meeting half-way

the time-frame of the project. This was taken serious by the JIGSAW leadership who facilitated the attendance of national patient champions at the network meeting in Liverpool in April 2018.



The aim of that meeting for the patients was to get to know each other better, to exchange experiences and to discuss how patient ambassadors can continue their involvement in

disseminating and implementing the project, also after funding of the JIGSAW-E ends. Apart from the advisory group, I work in particular together with the international PPIE support group that coordinates the patient involvement.

I also like to work on a national level as a patient champion in the Dutch project team. We have reviewed the translated osteoarthritis handbook, discussed cultural adaptations, suggested solutions for the lay-out, illustrations and dissemination strategies. We reviewed the Quality Indicator Questionnaire and were constantly involved in the report of progress by other stakeholders. So far this has been an enjoyable experience and I have learned a lot about osteoarthritis. And since the meeting in Liverpool I can also say that I have gained some real new friends.



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