

# Patient Champions in JIGSAW-E

Kathy Fell, UK

## How did you get involved in JIGSAW-E?

My name is Kathy Fell, and I live with my husband and our dogs in Cheshire, England. I have two grown up daughters and two grandchildren and I was diagnosed with sudden onset arthritis in 2011, after losing my job. My rheumatologist told me that it was probably made worse by the stress of this and starting the menopause. I had debilitating pain in both hands, one foot and my neck, I'd never experienced anything like this before. It took me some time to accept the diagnosis, I felt down and I struggled with the fact that my condition was here to stay.

Shortly after diagnosis, my Occupational Therapist suggested that I volunteer at Keele University, where they were conducting a new research study looking at thumb splints for osteoarthritis. Although I was nervous, I agreed and I joined the Research User Group. I've not looked back since! Along with other members of the group I have advised researchers on how to keep their studies patient centred and relevant and I have shared my experiences of osteoarthritis on several different projects.

In 2016 I was asked to be a Patient Champion for the JIGSAW-E project. I like starting new things with new people so I didn't hesitate to say yes. Before arthritis I was a computer programmer / analyst before taking time out to raise my family. After that I worked as a data administrator in a high school and I now work for the National Trust. My hobbies include dog training and keeping fit and I think these have helped me immensely with my arthritis. Exercise in particular has alleviated many of my symptoms.





## What is your role as Patient Champion?

I really enjoyed the launch event for the project when the Community of Practice came together for the first time. It was wonderful to see patients, doctors, physiotherapists, nurses, IT and project managers all together, learning about the different health systems across the different European countries involved in the project. The meeting opened my eyes to the potential challenges of implementing JIGSAW-E but I was struck by the willingness of the group to make it work.

Along with my fellow UK Patient Champion John, we met with other Patient Champions from the other countries and it was interesting to hear their experiences of osteoarthritis and how their healthcare systems differ to ours.

I have also been involved in looking at the patient Quality Indicators. We looked at the 15 questions on the Quality Indicators questionnaires from the UK and Norway and picked out the best versions to create one unified questionnaire to be used in the project. We made sure that the questions remained clear, concise, and relevant to patients.



I think that the JIGSAW-E project has benefitted from strong Patient Involvement - from the initial research during which the guidebook was created to the posters and leaflets which were created by patients during JIGSAW-E. The former has proved very successful and has now been translated into other languages for use by the other countries involved in project.

I think it's important to involve patients from the start of an implementation project. Patient involvement grows as the project grows. Involving patients isn't just beneficial to the project, it is also important to the patients. I never thought I could do something like this but I did!

The best part of JIGSAW-E is that we are looking forward not backwards and working as a team.



*Kathy*

Cheshire, UK