



**Report from a BTCure researcher and
Patient Research Partner
Heidi Wähämaa, Researcher, CMM, KI
Eva C Johansson, Patient Research Partner**

Heidi:

Our first meeting took place at a guesthouse breakfast in Birmingham. It turned out that both of us were from Sweden aiming to attend the same conference. Eva introduced herself as Patient Research Partner and this was the very first time I came in contact with this expression and the PRP concept. As we both were very keen to improve the communication between researchers and patients it was a natural step to continue the discussion. Without realizing we created a project and initiated collaboration based on our mutual interest.

Eva:

What we've done so far, project-wise, is that Heidi has put together a lecture on the inflammatory process and RA with me as her test panel. The aim is to develop material with a content and terminology acceptable to both layman and professional to be used at the clinic for patients and relatives, as well as, for students and new PRPs. Our respective roles and functions in this process is something we explore under way as we identify new issues which need to be addressed, discussed and clarified.

Heidi:

As in all professional roles it is important to create an open, honest and respectful relationship. However, the Researcher/PRP relationship might encounter additional obstacles compared to a common working relationship. For us who are researchers without clinical experience it might be difficult or even frightening to have contact with patients. Therefore, it is essential to understand that Patient Research Partners are not, in this context, patients but colleagues with unique competence.

Eva:

And this goes both ways. How do I convey my experience of RA to the medically trained researchers without slipping into the patient role? There is also a delicate balance here between the personal and the private, which is dependent on an open and respectful atmosphere. To help patient involvement in research along the way, Eular has put together a handy set of cards with guidelines for researchers, as well as, PRPs. These provide a solid base to build your collaboration from.

Heidi:

The research lab environment and its culture are unfamiliar for most of the PRPs. In order to establish a sustainable and fruitful collaboration with a team work spirit, it's essential to be inclusive. Inviting your new colleague to the research lab gives you a fantastic opportunity to introduce her for the entire research group and a possibility to explain and show different lab techniques of interest.

Eva:

The research environment in itself, with all its high-tech and terminology, can make me slightly hesitant of my role and ability to contribute. It's like stepping into a cockpit! But I remind myself that if the others are qualified pilots, I can contribute my knowledge about the



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weather and terrain. It's a very enlightening and creative process. One of my major functions is asking questions, it helps make knowledge visible - and the gaps; and it fuels discussions.

Heidi:

Working together is to develop communication in order to avoid miscommunication. We have to reflect, put in time and effort to be as clear and precise as possible about aims, intentions and expectations. Our primary aim was in regard to researchers and patients, however, the collaboration itself proved to be an ongoing exercise in communication in general. Although it can be challenging at times it is a very rewarding learning process. It has given me important insights how to improve my collaboration skills with co-workers and students. I'm happy we started talking over breakfast and got the discussion flow going.

Eva:

I can only agree. I really enjoy this, the learning curve, the challenge and the laughter.

Reference cards:

http://www.eular.org/myUploadData/files/Eular_Reference_cards_25-04-13_1.pdf

Brochure:

http://www.eular.org/myUploadData/files/Reference_cards_explained_Booklet_pages_23-08-13_1.pdf