NIHR | Oxford Biomedical Research Centre

The RUDY Study, Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences

Alison Turner, PPI Coordinator

What was your study about?

The RUDY Study is a novel web-based platform for participants with rare diseases that supports patient-driven research, allowing web-based registration, data collection, two-way communication and dynamic consent.

How did you involve patients and/or the public?

This study has had strong PPI representation from the beginning as we linked up with initially three patient groups who sent along members to the study launch day. This led to the formation of a patient forum that now has over 25 members. The patient forum provides a core group for RUDY and continues to be involved on a weekly basis through emails with myself and regular Skype meetings every six weeks. The charities also contribute by promoting us on social media and advertising within their charity groups for new members to sign up to the database, including children. The patients are invited to meetings to present their thoughts on RUDY. This year we held meetings with patient groups to discuss ideas for future research into their rare diseases.

One of our participants made an animation to explain RUDY:
https://www.youtube.com/watch?v=PyJ7IuJ0rAU

Several of our participants attend conferences and meetings to discuss their experience of RUDY. We are so proud of this as RUDY was created for the participants so to have some of them talk about their experience of being in RUDY is wonderful. Here is one talk given by a RUDY member: https://youtu.be/tv5o9KfYt08

What was the impact of involving patients and/or the public?

This has changed how we usually conduct research as we have introduced the idea of dynamic consent (with input from the PPI). Participants can change their consent options on the database, so as their situation changes so can their consent options. It gives a feeling of empowerment and of being in control as to how much involvement the participant wants to have. This involvement is not static and can be changed. We started with one consent form with lots of options on it; after feedback from the participants we have split the consent form into several smaller ones.

One of our RUDY patient forum members asked if she could promote RUDY whilst attending her clinic for chemotherapy treatment. We asked various PPI organisations if this is possible but couldn't find any evidence of this happening in other studies. We changed our protocol and received REC approval to enable RUDY participants to recruit other members into RUDY whilst they are attending clinic appointments.

The impact of the patient forum includes: choosing the study name RUDY and the logo, changing the RUDY recruitment and methods that required a substantial amendment,

reviewing new features for RUDY e.g. the medication module, suggesting new research questions such as sleep, economic impacts on job and schooling and including the effects on partners/family of affected patients.

As the study is concerned with rare diseases, and there is sporadic information regarding these diseases, the biggest resource we have is the participants themselves. They know more about the day-to-day impact of their disease than the clinicians so we also have asked our PPI members for ideas on future research projects. We have a representative on each of our committees from our PPI forum, including the data access committee, and these members feed back to the PPI forum regarding our committees and what has been discussed and agreed. We discovered early on that there needs to be a more coherent collection of rare disease information with the experts in this field working together to collate information.

We also hold weekly team meetings and the minutes from these are circulated to the group and we often have comments from PPI arising from these meetings. Members of the patient forum also suggest new aspects of the database. It is important for PPI to be involved as the RUDY database would not be successful if it wasn't user-friendly and so the PPI forum have helped to design the database to ensure it meets their needs. Their involvement also gives them a sense of pride and they in turn take pleasure in promoting the study.

What were the challenges and how did you overcome these?

The biggest challenge is access. As our PPI forum is made up of members from all over the UK getting everyone together is the most challenging aspect. Some of our forum members are in wheelchairs and so long distance travel is difficult for them. We overcome this by only meeting face-to-face once a year and the rest of the time we hold monthly/bi-monthly Skype meetings in the evenings. We did start with daytime Skype meetings but several of our members work and so struggled to attend the Skypes during the day. We now meet in the evenings. Dr. Javaid can share his screen view and so everyone can see the same thing, and we can all see each other, so it feels less like a teleconference and more like an informal chat.

We use these meetings to show the forum what we have been working on and ask them if they think it could work or if it should be changed. Before we launch anything on the database it is sent for rigorous testing by 8-10 PPI members. We ask them to try to break the database and to comment on things that they think should be changed. It means more work for the IT guys but ultimately it creates a workable database for the people who are actually going to use it. Technology really helps us keep in touch and virtual meetings are definitely the easiest way to meet regularly.