Oxford Biomedical Research Centre

Oxford Musculoskeletal Biomedical Research Unit

Patient and Public Involvement (PPI) in Research – Case Study

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How patients and the public were involved

Rudy Study — this is an novel web based platform for participants with rare diseases of bones, joints and vessels that supports patient driven research allowing web-based registration, data collection, two-way communication and dynamic consent.

This study has had strong PPI representation from the beginning as we linked up with initially 3 patient groups who sent along members to the study launch day. This led to the formation of a patient forum that now has over 15 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 6 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 including the 2015 NIHR RD TRC rare diseases day in Cambridge and the Oxford ELSI workshop on patient engagement in research.

The impact of involving patients and public in the study

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 consent forms.

The impact of the patient forum include: 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.

The importance of involving patients and the public in research

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 and the things they would like to see researched. 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.

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.

The biggest challenges in PPI and what might help to overcome them

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 day time 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 with the participants of the Skype 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.