

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

**Provided by:**

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**How patients and the public were involved**

Rudy Study — this is a web based database for participants with rare diseases of bones, joints and vessels. The participant (once fully consented) can complete the history of their disease on their secure web page, and complete questionnaires. There will also be the facility to date stamp and print out their history to take with them to their clinic appointments — this is especially useful for the brittle bone participants who have had numerous fractures.

This study has had PPI representation from the beginning as we linked up with several charities who sent along members to the study launch day. The members continue to be involved on a weekly basis through emails with myself and regular skype meetings. 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. Parents’ consent on behalf of their child and we plan to use the parents experiences to also look at the Health Economic side of things regarding the cost to the family of their child’s disease (such as time taken off work by the parent to care for their child). We now have ethical approval to recruit non-affected family members into the study.

**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.

We also have been lucky to have enthusiastic PPI members who have contributed immensely. From designing the logo of the study to changing the wording of the patient information leaflet, our members have been keen and happy to help all the way along.

**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.