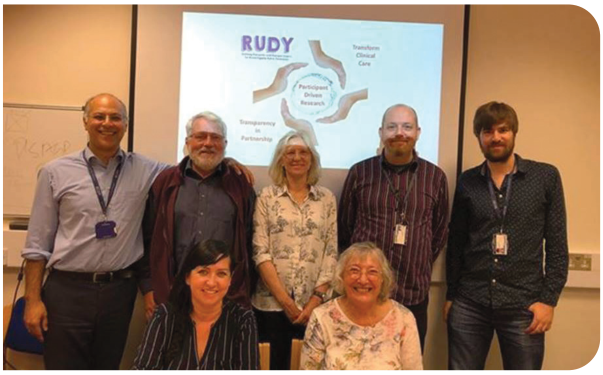
NIHR | Oxford Biomedical Research Centre

Patient and Public Involvement

The RUDY Patient Forum

Case Study



Background

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

This case study highlights the valuable contribution of the RUDY Patient Forum.

What we did

Patients were recruited to the RUDY Patient Forum initially through charitable patient groups. There are now over 25 members attending regular online meetings and engaging through email communications. Charitable patient groups promote RUDY and advertise for new members, including children.

What difference did it make

The RUDY Patient Forum has supported and influenced RUDY in a range of ways:

Dynamic consent has been introduced. This allows participants to change their consent options on the database, as their situation changes, giving control as to how much involvement participants want.

Talks and films: Members attend conferences and meetings to discuss their experience of RUDY. **This is a talk** given by a member. Another member made **an animation** to explain RUDY.

Ideas for future research: RUDY Patient Forum and patient groups regularly discuss ideas for future research into their rare diseases. New questions have been added including sleep, economic impacts on jobs and schooling, and the effects on partners/family of affected patients. As there is sporadic information regarding these rare diseases, the biggest resource we have is the participants themselves.

New data: A blood sample study was added to RUDY for myeloma participants, as well as a COVID-19 questionnaire.

Recruitment: A RUDY Patient Forum member asked if she could promote RUDY whilst attending her clinic for chemotherapy treatment. We gained REC approval to enable this.