

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

Provided by:

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How patients and the public were involved

I am currently in the process of setting up a James Lind Alliance (JLA) Priority Setting Partnership (PSP) under the guidance of Sophie Petit-Zeman, to address the research uncertainties surrounding rare inherited anaemias.

Prior to this, I set up an informal patient group for families with rare inherited anaemias. We met in November 2014 and I led a brainstorming session on what they felt would be the priorities in research on inherited anaemias. Through the variety of issues raised, we identified 4 common themes (targeted therapies for specific disorders, how to improve patient experiences of transfusions, how the different disorders are related and what are the psychological impacts on the family).

The impact of involving patients and public in the study

This is too small and too early to have had an impact, beyond that of encouraging me to carry on with the JLA PSP. I would hope that this has given the families some hope that the climate is changing and that their voice will begin to get heard.

The importance of involving patients and the public in research

Makes the research more relevant. Important for funding bodies to prioritise which proposals to fund.

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

Time!! This is yet another thing to fit into a schedule already bursting at the seams trying to do clinical work and lab work. The more support from dedicated sources there are, the better.