What's it like taking part in a consensus meeting?

"When asked to attend the core outcome meeting I was a bit worried about what it would be like. How would it be? Would I be able to help with any of my input? I was pleased when I got to the meeting to be greeted by the PPI coordinator who explained she was there to help and support the mums that were there. Once at the meeting I felt at ease as everyone was very friendly. It felt relaxed and not too formal. Thankfully I had the PPI coordinator there, she helped me, checking that I understood the questions throughout the day. To anyone that would be worried about taking part in one of these studies please do not worry it is actually an interesting, enjoyable day. I left the meeting feeling happy that I had been able to help." **Claire Pinnington, parent, bronchiolitis core outcome set.**

"In 2016 I (a 48 years old patient with a rare neuromuscular disease) was invited to attend a workshop for experts in my particular disease. I was very nervous, because we are talking about researchers and clinicians from all over the world who have expertise knowledge and experience. I did not really know what was expected of me. But when I was sitting at the table with all 20 of them I realised this: I may not have studied the disease, but I LIVE it everyday. That makes me be an expert in my own right! And in the end we were all there because, despite our differences, we share the wish to know more about and in the end cure this disease. And we cannot do that without the other! This helped me to speak up. I told them this was all very new to me and they realised the whole thing could be overwhelming the first time. But they took me seriously, listened and some of them asked me questions during discussions: "Ingrid, as a patient what is your view on this matter?"" **Ingrid de Groot, patient, myositis core outcome set**