

Nothing About Us, Without Us: The Impact of PPI in MASTERPLANS

Executive Summary

**Dr Liz Mellon, Professor Ian Bruce and Dr Gillian Armit on behalf of
the MASTERPLANS Consortium**

(*contributors are listed at Appendix 3)

Executive Summary

The £4.5M, MRC-funded MASTERPLANS research (June 2015-February 2021) investigated how different groups of patients with Systemic Lupus Erythematosus (SLE) respond to treatments. The MASTERPLANS Consortium comprised 9 UK universities and 9 pharmaceutical and bioscience companies. MASTERPLANS originally intended to run its own clinical study (PLANS) but was very slow to recruit, as so few patients met the criteria for inclusion in the study, leading to the closure of PLANS in December 2017.

PPI was involved in MASTERPLANS from the outset, with the PPI lead working with Professor Ian Bruce, the Principal Investigator (PI), on the grant application in 2013, writing the PPI paragraph in the grant application and attending the review meeting to support the application. As the project unfolded, 18 patients, or their relatives, were recruited and over the life of MASTERPLANS participated in every work-strand committee and project management committee.

As MASTERPLANS drew to a close, we were keen to assess whether PPI was successful and where improvements might be made. A small working group met to design an open-ended questionnaire, which was administered via phone. 28 patients, researchers and project managers responded. The transcripts (each approved by every interviewee) are now held in the research data storage system at Manchester University, password protected, with permission granted for their use in further research.

Overall, we can conclude that PPI in MASTERPLANS was a success. Specifically:

1. The majority of patients and scientists reported benefiting personally from PPI.
2. The majority of patients and scientists reported that the project had benefited from PPI.
3. The majority of patients and scientists reported making changes as a result of PPI.
4. There is harmony in the responses to questions about what should have been done differently during MASTERPLANS and what the respondents intend to do differently when involved in future research. This implies that real learning has taken place about best practice in PPI and is being taken forward into new projects.

While we consider PPI in MASTERPLANS to be a success, the full report offers suggestions and questions for other similar research projects to consider.