

Patient Representative in the ToTem Trial Management Group

One example of how patients and the public can be involved in health care research is as a Patient Representative in the Management Group of a clinical trial.

This is exactly what Gillian does. She is involved in an early phase clinical trial, called 'Transfer of effector memory T cells (Tem) following allogeneic stem cell transplantation or in short ToTem.

The ToTem study is a phase I clinical trial testing the dose of a memory T-cell product to enhance general immune reconstruction in patients undergoing haematopoietic stem cell transplants (transfer of stem cells, which lead to new blood cells in the recipient). The trial is part of the UCL Blood and Transplant Research Centre managed by a team at the Cancer Research UK (CRUK) & UCL Cancer Trials Centre (CTC), including Gillian as the Patient Representative.

Gillian is a member of the CTC's Patient Advisory Group (PAG) using her expertise as a former patient and clinical trial participant to advise on trials. After the Senior Trial Coordinator reached out to the group, she decided to join the ToTem Trial Management Group. Gillian provides a patient perspective to the team, which supports the Principal Investigator, Trial Coordinators and Statisticians in setting up and managing the study, which opens in Summer 2019. When Gillian first joined the group, the Principal Investigator set up an informal call to chat with her about the study. Gillian now attends Trial Management Group meetings that take place every six months to discuss progress of the trial. In preparation for the study she recently reviewed all patient-facing materials ensuring that documents were easy to understand and clearly written for patients invited to take part.

"Having someone that has direct experience as a patient providing their view on the trial is very important. Their insight on patient-facing documents in particular is always highly valued."

Darren, Senior Trial Coordinator

Moving forward Gillian will continue to provide a patient perspective on different aspects of the study. The facilitator of the CTC's PAG supports Gillian in her role and she can consult with other members about any questions relating to the study and her involvement. Gillian's viewpoints and input to the trial is benefiting trial participants and health research, ultimately leading to improved health care for patients.

Find out more about the [ToTem trial](#)