

In collaboration with

- Guy's and St Thomas' NHS Foundation Trust
- University College London Hospitals NHS Foundation Trust
- University of Oxford
- NHS Blood and Transplant

Transfusion Practice Panel

Summary

We are recruiting approx. 30 patients/members of the public to join a new Patient and Public Involvement (PPI) Panel. We would like to recruit people who are interested in blood transfusion research and the practical aspects of successfully transfusing blood from donor to recipient. The Panel will be the umbrella for multiple streams of work (and more could be added in time):

- **HAEM-MATCH Consortium** (see accompanying plain English summary)
 - The overarching objective of the HAEM-MATCH Consortium is to reduce the risks associated with blood transfusion treatment given to Sickle Cell Disease patients. It consists of overlapping research projects, underpinned by a bioinformatics (collecting and analysing complex biological data) component. The aim is to develop understanding of blood group matching and prevention of blood group antibody formation to make transfusion safer for patients.
- **ROTHEM**
 - Return of the Microvesicle: A study looking at the role of microvesicles (broken off bits of red cells) in sickle cell disease
- **Component Development**
 - NHS Blood and Transplant (NHSBT) provide different components for patients—the most commonly used in patients with red cell disorders is packed red blood cells. There is an aspiration to do some research into frozen blood and blood from cell salvage in the future.
- **Other studies related to transfusion in red cell disorders**

Panel members will be unpaid volunteers, but reasonable travel/access requirements will be reimbursed. They will lend their individual perspectives to key discussions about different aspects of blood transfusion, databases, IT infrastructure and ethical issues, such as large scale genotyping.

Our ambition is to draw on the principles of co-production on how we work together, building high quality relationships and valuing your thoughts and perspectives as a key part of the research process. We know that public contributors can help make research better and more useful.

Specific Responsibilities for Patients/Public:

Panel members are unpaid volunteers. We welcome as much input/participation as you feel comfortable to give.

- Provide feedback on:
 - Plain English research summaries
 - Information for patients for study recruitment
 - Study protocols
 - PPI sections of funding applications
- Return feedback to the PPI Lead(s) by the deadline
- Attend workshops to learn more about specific research projects and participate in discussions
 - Workshops will be attended by PPI Leads and, possibly, researchers and may be in person or via video call
- Attend and participate in public engagement events
- Join Advisory or Steering Committees for specific projects or studies

Volunteer Specification

- Interest in and commitment to improving health and social care
- Be able to maintain confidentiality
- Have the time to attend meetings and read documents beforehand
- Be willing to learn about the blood transfusion process with the research team
- Have access to a computer and email (desirable)

If interested, please contact Sarah Fahle (srf42@medsch.cam.ac.uk)

This Panel consists of:

- Dr Rachel Kesse-Adu, Consultant Haematologist at Guy's and St Thomas' NHS Foundation Trust (GSTT; Chair)
- Dr Sara Trompeter – Consultant Haematologist at NHSBT and University College London Hospitals (UCLH) NHS Foundation Trust
- Dr Katrina Fordwor – Specialist Registrar in Haematology, Oxford
- Dr Sarah Fahle – Research Programme Manager at the University of Cambridge (Blood and Transplant Research Unit (BTRU) in Donor Health and Genomics)
Website: www.donorhealth-btru.nihr.ac.uk
Twitter: @DonorHealthBTRU