

Workshop on Participant Data Sharing

On the 1 November 2018, the UKCRC Registered Clinical Trials Unit (CTU) Network hosted a workshop in Leeds to explore issues relating to the sharing of individual participant data from clinical trials. This one day session was the result of work undertaken by the Network's Participant Data Sharing (PDS) Group following on from their invited panel session at the ICTMC/SCT Joint Conference in Liverpool in May 2017.

The aim of the Workshop was to highlight the latest developments in the field of clinical trial data sharing and provide practical tools to help CTUs develop data sharing systems that incorporate good practice. The mixture of presentations, Q&A and discussion sessions, and opportunities for networking provided clinical trial unit data sharing representatives with an opportunity to share experiences, and gain advice from experts in the field of data sharing.

The event welcomed 55 delegates from 46 academic Clinical Trials Units across the UK and Northern Ireland, and brought them together with representatives from a number of different groups whose remit covers data sharing. This included: NHS Digital, funders, the UK Data Archive, and the UK Anonymisation Network amongst others. There were also speakers from several Registered CTUs and a video presented by a patient representative member of the PDS Group outlining discussions that she had had with patient representatives in other forums.

The agenda covered a variety of topics ranging from a session on Anonymisation, which included an overview from the UK Anonymisation Network and the practical experiences of a CTUs as they developed their data sharing policy and practices, to an outline of the Current Data Sharing Landscape and the Funder Perspective lead by speakers from Cancer Research UK and the NIHR. Other sessions looked at data sharing from the Patient Perspective and considered issues relating to Data Use Agreements. Dave Cronin of NHS Digital, was also joined by representatives from the UK Data Archive and Gill Booth, Chair of the Network's QA Operational Group, in a session looking at the current Regulatory Context.

Catrin Tudur Smith, Chair of UKCRC Registered CTUs Network's PDS Group stated

"The event has been an excellent opportunity for clinical trial data sharing representatives to meet and share their experiences, as well as to engage with experts with knowledge of the current relevant regulations, and to see how data sharing is approached in different research environments."