

Joint Workshop on Access to Routine Data from NHS Digital

On the 26 January 2018, the UKCRC Registered Clinical Trials Unit (CTU) Network and NHS Digital hosted a joint workshop in Leeds to explore issues relating to access of routine clinical data through NHS Digital processes. The one day workshop, which welcomed 47 delegates from 35 Clinical Trials Units from across the UK, was the result of discussions which had been taking place between NHS Digital and representatives from the Network. The agenda included a discussion on priorities identified by the NIHR Efficient Trial Conduct project which is exploring ways in which making requests to NHS Digital can be made easier for clinical trials. The workshop sought to build on this ongoing work and further develop collaborations between the Network and NHS Digital.

During the morning session, Terry Hill, Gaynor Dalton and Louise Dunn of NHS Digital described the key changes which had been undertaken in relation to the Data Access Request Service (DARS) system, provided guidance to CTUs in respect of making and amending submissions, and discussed the potential ways in which the process could be streamlined to support applications. Delegates were also invited to provide feedback on the DARS and give their suggestions for other changes that they felt might raise awareness and further improve the user experience.

The afternoon session focussed on preparations for the implementation of the National Data Opt-Out & the General Data Protection Regulation (GDPR) and delegates were able to explore the practical implications relating to opt-outs and the legal basis in more depth.

Delegates were also given the opportunity to share knowledge and best practice in relation to the principal requirements of the application process and use of data which identified areas which they felt needed to be addressed going forward. This discussion session was broken down in to four key themes: 1) organisational level procedures within CTUs, 2) trial level procedures at the pre-application stage, 3) making an application to access data, and 4) trial level procedures post application. This gave an opportunity to collate information on key areas of concern to inform future work.

As part of its on-going commitment to support the work of its members, the Network has now established a Task and Finish Group to work with NHS Digital and other key stake holders to identify and progress priorities in respect of accessing routine data. The Group, which will be chaired by Duncan Appelbe of the University of Liverpool, will undertake a scoping exercise over the next few months in order to further define its activities and the comments and queries noted at the Workshop will be included in this review.

Saeeda Bashir Programme Manager of the UKCRC Registered CTUs Network stated *“The event has been an excellent opportunity for the academic clinical research community to engage with NHS Digital and feedback on vital policies and processes that significantly affect our research. We welcome the collaboration and are excited about future joint projects”*.