

Data Trust Committee - Quarterly report (February 2022 – April 2022)

The purpose of the quarterly report is to ensure transparency of Data Trust Committee processes and to highlight the impact that the committee's input has on PIONEERs work.

Toplines:

Number of meetings	3
Number of requests reviewed	5
Total number of requests approved	5
Tot number of requests not approved	0
Number approved with conditions*	0
Number approved after amends* requested	0
Number of approved with data licence pending*	0

* Included within the total number of requests approved.

Projects approved (note projects are not reviewed in numerical order):

PDR053 - RealWorld Health - End stage renal disease
 PDR054 – Sudlow – SARS-CoV-2 vaccine safety
 PDR055 – Bangash – NT-proBNP dynamics in critically ill patients
 PDR056 – Witham – ADMISSION programme study
 PDR057 – Kamwa - Interactions of frailty, age & illness severity on outcomes in COVID-19

For each of the approved requests, a lay summary will be available on our website. Note, requests are not necessarily reviewed by the Data Trust Committee in numerical order but based upon an evaluation of priorities.

Other Updates:

- As previously reported PIONEER has prepared a short animation piece that is available on our website that supports the 'Your data could save lives' campaign. The animation has been created to allow patients and the public the opportunity to visually see the importance of allowing health data to be securely shared with researchers, etc. to help save lives. This animation has been well received and has had a number of views.
- The finalised version of a user-friendly guide to completing the Data Request Form has been created. This is now being sent to all requestors to ensure

completeness of the form and to answer general queries. It details what the Data Trust Committee are looking for to support their recommendations, as well as providing requestors with a guide to completion of a Data Request form.

- A short programme of activity to encourage new members of the public and patient community to join the Data Trust Committee has been undertaken with some success. We are in the process of arranging initial training/on boarding of the new members of the Committee.