

## Data Trust Committee - Quarterly report (November 2021 – January 2021)

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	6
Number of requests reviewed	11
Total number of requests approved	10
Tot number of requests not approved	1
Number approved with conditions*	2
Number approved after amends* requested	2

\* Included within the total number of requests approved.

### Projects approved:

PDR014 – Shallcross – Secondary bacterial resistance  
 PDR015 – Couper and Beeston – Machine learning and pneumonia  
 PDR016 – Kenyon – Maternity presentation in emergency department  
 PDR017 – Schmidt – C-reactive protein  
 PDR018 – Kamwa – Frailty  
 PDR019 – Atkin – Emergency department admissions  
 PDR020 – Kay Por Yip – Covid-19 and COPD  
 PDR021 – Parekh – Covid-19 ventilation  
 PDR022 – Ashraf – Covid-19, AI and chest x-ray  
 PDR023 – Ball – Virtual Covid-19 ward

For each of the approved requests, a lay summary is available on our website. The above list all link through to the summaries published to date.

### Projects not approved:

PIONEER received a data request from a USA based insurance company, seeking to explore how premiums should be set for those with complex health needs, by assessing unplanned healthcare contacts. The PIONEER team discussed this with our Data Trust Committee and HDR-UK to ensure our thoughts and actions reflect their opinions on the matter.

PIONEER declined this request on the following grounds:

1. The potential benefit for patients was unclear, especially if the activity could reduce the ability of some people to access healthcare.
2. Patient/public trust. Public consultation has raised concerns about health data sharing with insurance companies. This would need significant public input to ensure acceptability.

#### Other Updates:

- The committee discussed and decided upon a process for urgent requests. This was pressing since several urgent data requests had been submitted in relation to Covid-19 research.

The committee agreed that they wanted to support these urgent requests and would be happy to meet more regularly, and for initial data scoping (not sharing) to begin pending their review.

#### Reflections on impact from the group:

- Committee members find it interesting to learn about the projects PIONEER would like to support and appreciate the opportunity to ask questions and to feedback to researchers.
- The PIONEER team find it helpful to have health-related research questions explained to them. Discussion within the committee makes the team think about health and data sharing in a different way.
- Questions from the DTC about one request inform how the PIONEER team approach Data Requestors when working up the next data request form, so the learning is taken forwards.
- The committee have noticed request forms becoming easier to read, and the aims and benefits to the public being highlighted more clearly.
- The committee are particularly focused on whether the requestors have appropriate public involvement planned for their own work, and so the PIONEER project team have made more effort to expand the support we provide requestors in this area.
- It is not clear how much benefit the requestors gain from our review process. To address this the DTC are planning to seek feedback at the end of the process through surveys etc.
- The DTC plan to demonstrate the committee's impact through testimonials from different perspectives published on our website, i.e. public, team and researcher.