

PIONEER Data Trust Committee

Annual Report

2024



Contents

Foreword.....	3
1. Executive Summary.....	4
1.1 Public involvement in data access decisions.....	4
2. Introduction	5
3. Committee Structure and Operations	6
3.1 Current membership	6
3.2 Recruitment and training of lay members	6
3.3 Meetings held and decision-making process	7
Three outcomes from DTC discussion are possible:	7
4. Overview of Data Requests.....	8
5. Public and Stakeholder Engagement	9
5.1 Public and Patient Involvement and Engagement (PPIE) Activities	9
Uniting for Health Equity:	9
Heartlands Hospital UHB Research Open Day:	9
5.2 Acute Care Public and Patient Group	9
6. Conclusion.....	10

Foreword

At PIONEER we believe that access to highly detailed, individually linked health data, supported by expert consultancy, can transform healthcare for our population.

Working in partnership we are improving the health and well-being of patients through our increased understanding of acute illness, faster diagnostic timelines, novel healthcare pathways and better treatments.

We achieve this through responsible and patient/public endorsed data sharing.

PIONEER uses vast amounts of health data from millions of members of the public; therefore, it is

vital that we talk openly about the work that we are doing. Not only is it right to engage with the members of the public whose data is held, it is also very valuable in shaping the research in line with the public's best interests.

Through a variety of engagement and involvement activities, we are reaching out to people all across the Midlands and further afield – seeking patients' insights, needs, and experiences. In doing so, we hope to build trust and enthusiasm for the great potential that health data research and innovation offers.



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1. Executive Summary

1.1 Public involvement in data access decisions

We continue to operate a Data Trust Committee (DTC). This group of 14 lay members, recruited through open application, review every data request, and provide an opinion as to the possibility for patient and public benefit versus the risks of data access. The group includes >40% BAME representation as well as members who self-define themselves as living with a long-term health condition, having physical and mental disabilities, and members of the LGBTQ+ community. 80% of quorate membership must approve data access before data access is agreed (pending legal contracts) and a decision not to support data access by the DTC is binding for PIONEER.

During the last 12 months, the DTC has expanded, changing to two groups meeting every two weeks, with increased feedback from data requestors as to how interactions with the DTC improved their project. These changes followed the DTC reviewing their processes and impacts.

Our PIONEER Public and Patient Group (PPAG) have co-written 34 project lay summaries, all published on our PIONEER website and used in social media campaigns:

<https://www.pioneerdatahub.co.uk/project-summaries/>

These highlight the benefits of health data research and the patient and public involvement in our processes. Feedback on social media has been highly positive.

Recognising the importance of public opinion in shaping research practices, the PIONEER team collaborated with a specialised agency to conduct public consultations specifically focused on federated analytics. By gathering feedback and insights from the public, we ensure that our research endeavours are guided by the values and preferences of the communities we serve. This active involvement of the public in shaping our research agenda reinforces our commitment to ethical and responsible data research practices.



2. Introduction

This report focuses on the work that the PIONEER Data Trust Committee (DTC) have undertaken throughout the year as well as highlighting some key aspects of their work.

The DTC is a patient and public committee which reviews all data access requests which are submitted to PIONEER and forms a decision as to whether data access has DTC support, to advise and guide the PIONEER Director/ Deputy Director and Information Asset Owner on behalf of the Data Controller.

The DTC is made up of voting individuals, who will have a term on the DTC of up to four years, with the potential to reapply for a further term. The DTC are assisted by experts in data research, information

governance, and UK data law; though these experts have an advisory capacity only and are not voting members of the DTC.

DTC membership includes a Terms of Reference and a Code of Conduct.

PIONEER is carefully managed with clear governance and accountability. All processes have been approved by the Health Research Authority (HRA) as well as the Confidential Advisory Group (CAG) and PIONEER reports all data access requests to the East Midlands-Derby Regional Ethics Committee that approves PIONEER on an annual basis.

Data access is under license and needs to meet the 'Five safes' criteria, which are:



Safe Data

We assess the risk that a person could be identified from the data and minimise this so that privacy is protected.



Safe Projects

We ensure the requested use of the data is appropriate, that it won't discriminate against any groups of citizens and that the knowledge gained from the data will lead to public good.



Safe People

We review who the data requestors are, and undertake a due diligence assessment, to check that the researchers can be trusted to use the data appropriately.



Safe Settings

We build Trusted Research Environments for data analysis. These secure environments have been cybersecurity tested and meet specific international ISO standards, meaning we control who accesses the data and what they do with it.



Safe Outputs

We examine all outputs from data analysis and ensure that the results can not cause any individual to be identified.

3. Committee Structure and Operations

3.1 Current membership



Includes people with physical disabilities, people with mental ill-health, carers and people with multiple long-term conditions

An important group for public involvement in PIONEER is the recently appointed PIONEER Public Advisory Group (PPAG). This group includes public members interested in unplanned and emergency healthcare, or acute care, and how we can improve health services for patients. Members of the PPAG

will have the option to be involved in different activities related to grants that PIONEER is part of, like the NIHR Birmingham Biomedical Research Centre, HDR UK Medicines Driver Programme Acute and Chronic Care theme, and others.

3.2 Recruitment and training of lay members

All members of the DTC undergo a specific training course over a three-week period prior to attending a meeting. An example training course schedule is:

Week 1:

- Read Role Profile and Terms of Reference Documents
- Induction meeting (part 1) – Introduction to PIONEER, summary of PPIE work and the way the Data Trust Committee works now.

Week 2:

- Watch 6 videos from the online seminar series
- Read the PIONEER protocol V3.0 document, link here <https://www.pioneerdatahub.co.uk/public-documents/pioneer-protocol-10-april-2021/attachment/pioneer-protocol-v3/>

Week 3:

- Induction meeting (part 2) – Share the data request form, the decision-making process and provide opportunity to ask any questions after the previous weeks independent learning.

Week 4:

- Listen into first DTC meeting and buddy up with existing members to support in preparation for the next meeting.
-

3.3 Meetings held and decision-making process.

Year	Attendee No's	DRF's reviewed
2021	86	29
2022	79	20
2023	88	18
2024	38	9

A Standard Operating Procedure governs the decision-making process.

The DTC have an advisory role within PIONEER, and although the views of the DTC are central to supporting or not supporting data access, the DTC have no legal obligations or powers to release NHS data under licence, as this remains under the control of the Data Controller.

The DTC will aim for a unanimous decision to support or not support the data access request.

Where a unanimous decision cannot be reached through discussion, an 80% majority (or nearest approximate) rounded to the nearest whole person, will be accepted to support the data access request.

Three outcomes from DTC discussion are possible:

- A recommendation will be made to support the data access request (either unanimous or not unanimous)

- A recommendation will be made not to support the data access request (either unanimous or not unanimous).
- A request for more information to address unanswered questions or a request for amendments to the DTC will be made.

Each member of the Committee will be asked in turn to vote to either support or not support the data request.

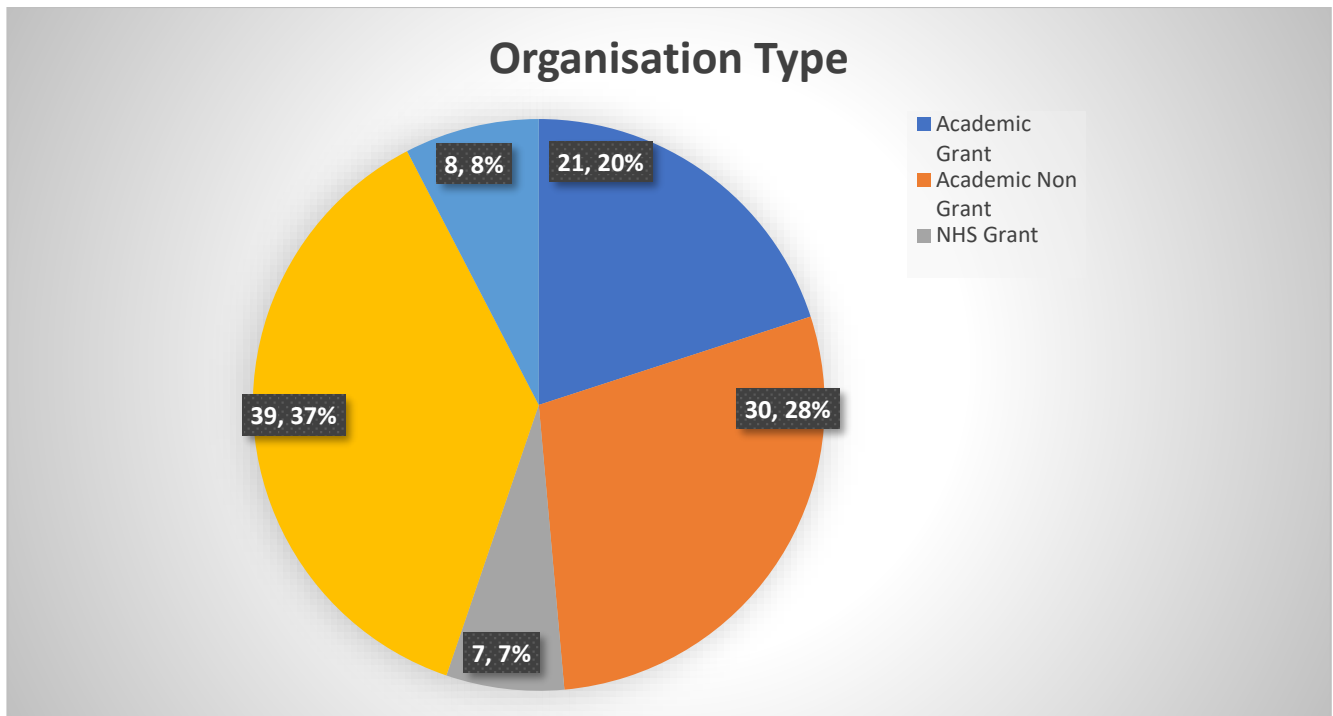
Votes will be stated person by person with the secretariat documenting the overall count.

Members can choose to abstain from voting if they wish, but the meeting will still be regarded as quorate, and their vote will not be counted in the 80% decision threshold. For example, if there are 9 DTC members and all vote, 8 are required for data approval. If one abstains, 7 will be required for data approval.

4. Overview of Data Requests

An overview of data requests processed and a breakdown showing the different sectors involved. The DTC committee members have been involved in all of requests.

Total 105 data requests to date:



5. Public and Stakeholder Engagement

5.1 Public and Patient Involvement and Engagement (PPIE) Activities

Uniting for Health Equity:

BRC Black History Month Community Event - PIONEER Hub participated in the Uniting for Health Equity event during Black History Month. Our PPIE lead and two acute clinicians were present to discuss ongoing projects and the research supported by PIONEER. The interactive stand engaged approximately fifty attendees, receiving positive feedback from both event organisers and the public. The photo (right) is of the some of the PIONEER team at our stand.

Heartlands Hospital UHB Research Open Day:

At the Heartlands Hospital for UHB Research Open Day, PIONEER Hub set up a stand featuring our PPIE lead and team members to discuss PIONEER's work and answer public questions. We also showcased the "Your Health Data Saves Lives" video (<https://www.pioneerdatahub.co.uk/your-data-could-save-lives/>), and distributed supporting flyers in five commonly spoken languages including Cantonese, Somali, Arabic, Polish, and Urdu. A large print version was also produced. This event attracted over 250 attendees, providing a significant platform for public engagement and information dissemination.



5.2 Acute Care Public and Patient Group

In addition to these events, the PIONEER Hub team have been establishing an Acute Care Public and Patient group. The flyer for this group was co-developed with public input, and we have already begun signing up members. Efforts have been made to ensure the group is representative of the diverse population of the West Midlands, covering a wide range of ages, ethnicities, and health needs.

This group is divided into key subgroups to support various research grants PIONEER is working on. Their activities have included co-developing three scripts for public-facing animations:

- Antibiotics Animation** The first animation explains the importance of identifying the correct virus or bacteria to prescribe appropriate medications and avoid antibiotic resistance. Once the animation was complete, we sought feedback from 2 additional public groups which has been incorporated into the next version. The final revisions are in progress, focusing on the speed of narration, colour choices, and clarity of the message to ensure it is jargon-free.
- Clinical Decision Support Tools Animation** This animation aims to explain clinical decision support tools in lay language, supporting PIONEER's development of tools for healthcare workers and keeping the public informed and engaged in the development process. A clinical

decision support tool is a health technology system design to provide healthcare professionals with assistance to make decisions. These tools offer tailored information, alerts, reminders, and guidelines to enhance patient care.

- c. **Drug-Drug Interactions Animation** The third animation, which is still in the storyboard phase, will explain drug-drug interactions (DDIs). DDIs

occur when the effects of one drug are affected by the presence of another drug. These interactions can result in various outcomes, ranging from reduced effects for the medication to an increased risk of adverse effects. DDIs can be complex and are influenced by other factors such as the drugs involved, their dosages, the patient's health status and other individual factors. This script has been co-developed with the public to ensure relevance and clarity.



Figure 1: One of the opening images showing antibiotics overflowing from a container.

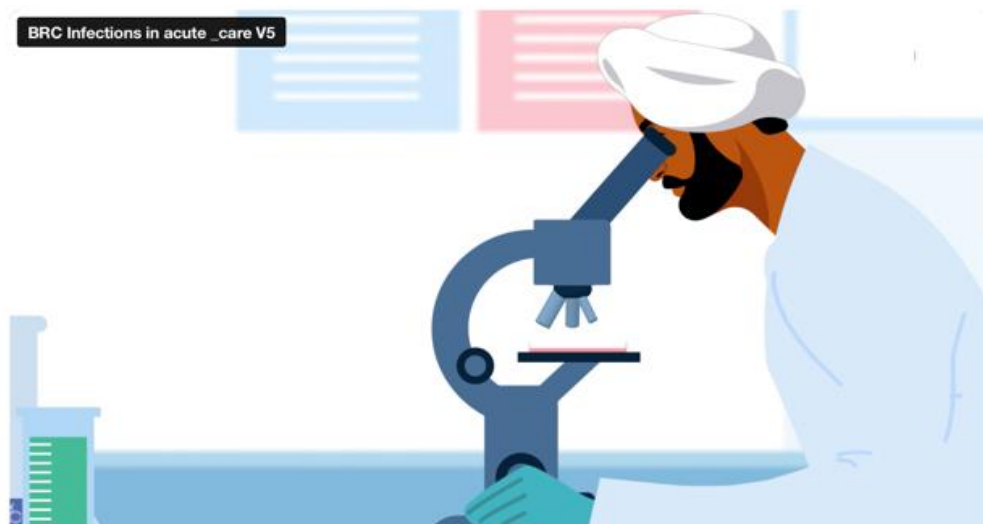


Figure 2: Animation showing how scientists can examine the virus and bacteria to understand what drugs will be effective.



Figure 3: Animation that explains with research, PIONEER are seeking to work with the Birmingham Biomedical Research Centre to understand illness and provide guidelines to ensure the right antibiotics is given for the right infection at the right time.

These PPIE activities underscore PIONEER Hub's commitment to public engagement, transparency, and ethical research practices. By continuously

involving the public in our work, we aim to build trust and ensure that our research aligns with the needs and values of the communities we serve.



6. Conclusion

We continue to work closely with our Data Trust Committee, a group that currently comprises 14 lay members who we have trained and offered ongoing support to understand responsible health data use. They meet twice a month to discuss data requests that come to PIONEER.

We intentionally recruited for diversity within this group. As well as demographic diversity and a range of experiences of using the health system, we also have some members who have previously worked with data, others with little prior knowledge, some

who have played a role as a public contributor in relation to medical research for many years and others for whom this is brand new. As far as possible, this group reflects our local population and brings a mix of background and expertise.

The integration of the Data Trust Committee as an integral part of our processes ensures that public oversight is key throughout all decision making. Working in this way also helps to build trust in our work from the wider public.

For more information on how PIONEER can help, please email:

pioneer@uhb.nhs.uk.

To learn more, visit our website at

www.pioneerdatahub.co.uk

