**PIONEER Data Trust Committee (DTC)**

Role profile for PIONEER DTC lay members

**Background:**

PIONEER will link data from unplanned health care touchpoints to better understand patient experience. By using big data to understand the acute care experience of patients, there is an opportunity to identify critical points in delivery pathways where new approaches, treatments and devices might revolutionise care.

Patient and public input has been embedded into the structure of the project with a patient panel, known as the Data Trust Committee, having full oversight of research using the data and advising the governing and scientific arms of the project. This input is key to ensuring all research coming out of the project will better meet the needs of patients and that it is carried out in a transparent and accountable way.

The Data Trust Committee consists of up to 9 voting members of the public. They will be supported by a team of non-voting professional advisors.

**Member responsibilities:**

The lay members will:

- review of all data request applications and feedback comments to the Scientific Steering Committee
- review lay summaries and communications materials to ensure accessibility and transparency
- advise on a particular areas and issues
- advise on the strategic direction of the programme

All members of the DTC must declare all relevant conflicts of interest, including any relationship to Data Requestors, or any stocks or shares held in relevant industry stakeholders.

Members are required to sign a confidentiality agreement.

**Member involvement:**

- reading data request forms and communications materials
- feeding back by email
- attending monthly meetings (maximum of 2 hours)

Meetings are currently held remotely by video conference. Ideally the group will meet face-to-face at least a couple of times a year (once it is safe to do so).

Whilst eventually the expectation is that group members would join one meeting a month, to begin with there are likely to be more as the group forms (approx. fortnightly).

PIONEER
Health Data Research Hub

**Support available:**

Members of the DTC will receive basic training to improve their knowledge of the research project and to upskill them to review data access requests appropriately. Throughout their term they will be supported by the Patient and Public Involvement and Engagement Lead.

**Duration of the role:**

Members of the DTC will commit to a minimum one year membership, to be reviewed annually, with length of service of any one individual member exceeding no more than four years.

**Payment and expenses:**

Lay members are paid an honorarium for each meeting attended (£75 per meeting, which includes the time required to do pre meeting work).

PIONEER
Health Data Research Hub