Use of health data by the life sciences industry

A UK perspective
Primary research, interviews and analysis gained from over 150 industrial partners between January and June 2019, including large pharmaceutical, biotech, medtech, diagnostics, contract research, data intermediary and technology companies and consulting firms.
• 92 separate data access request attempts were recorded
• Data type with the highest attempt rate was clinical trial data (22% of responses)
• Data type with the lowest attempt rate was administrative secondary-care data (5% of responses)
• High demand for clinical real-world data from electronic health records, disease-specific data (registries) and genomics data
Most companies have experienced delays and uncertainties in accessing data:

- 43% reported cost barriers
- 39% reported access constraints (including lack of commercial consents) as a barrier
- 37% reported identification and quality assurance of data sets as a barrier
- 35% reported the time taken to access data as a barrier
Of 92 separate data access requests recorded, only 25% were deemed completely successful:

- 45% of clinical trial data access requests were successful
- 43% of electronic health record data access attempts were unsuccessful
- Access to primary care data was of limited success with no fully successful attempts reported
Six themes emerged from the engagement with the pharmaceutical and life sciences industry on what they say it needs from health data:

- **Data breadth, depth and scale**
- **Speed of Access**
- **Quality**
- **Expertise**
- **Public Trust**
- **Affordability**
UNITING THE UK’S HEALTH DATA TO MAKE DISCOVERIES THAT IMPROVE PEOPLE’S LIVES

UK HEALTH DATA RESEARCH ALLIANCE
Uniting the UK’s health data

UK Health Data Research Alliance

NHS DATA
COHORT DATA
REGISTRY DATA
TRIALS DATA

HEALTH DATA RESEARCH HUBS
Curating disease focused datasets and providing clinical trials and real-world evidence services

HEALTH DATA RESEARCH INNOVATION GATEWAY
Finding and accessing nationally aggregated, usable data

DISCOVER
DE-IDENTIFY
LINK
ACCESS
ANALYSE
PHENOTYPE LIBRARY
LINK TO TRUSTED RESEARCH ENVIRONMENTS (SAFE HAVENS)

USERS:
Researchers, Industry, NHS, Charities and Government

Operated by
Health Data Research UK

PATIENTS

PATIENT AND PUBLIC BENEFIT
Participants of the research, the members of the pharmaceutical and life sciences industry and the wider stakeholders in medical research in the UK who gave invaluable insights via workshops, structured interviews and an online survey.