

DATA-CAN Collaborative Agreement – lay summary

This is a short summary of the agreement between the ‘Founding Partners’ (i.e. the original partners) of [DATA-CAN: The Health Data Research Hub for Cancer](#). This summary focuses on areas that may be of interest to the general public and patients.

Different agreements are in place regarding any further partners (called ‘Associate Partners’). This is because the Founding Partners are supported by [Health Data Research UK](#) and funding from the Government’s [Industrial Strategy Challenge Fund](#).

DATA-CAN’s Founding Partners commit to observe the Digital Innovation Hub programme’ eight [principles of participation](#). These principles include:

1. Demonstrating active and ongoing engagement with patients and the public
2. Encouraging the availability and use of structured and unstructured health and care data
3. Making data **F**indable, **A**ccessible, **I**nteroperable and **R**eusable by adopting the FAIR Guiding principles for scientific data management and stewardship.
4. Adhering to the Foundation Principles and Core Elements for Responsible Data Sharing
5. Maximising the benefits of data for research and innovation through non-preferential access to data for uses that serve the public interest
6. Establishing mutually beneficial ways of working in partnership
7. Working collaboratively to increase harmonisation
8. Contributing to a joined-up and UK-wide offer for researchers in all sectors by collaborating with existing, relevant health research infrastructure.

All access to data must be in accordance with UK law:

- ✓ Any data access provided by data controllers (who decide what to do with the data that’s been collected) must be through a ‘Safe Haven’. This is a controlled and secure IT environment for undertaking research involving sensitive data. Sensitive data is defined as confidential, personal or legal ‘special categories’ data, or data likely to cause harm if breached.
- ✓ Any work on ‘identifiable’ data (i.e. data from which individual patients or healthcare professionals could be identified) will require a risk assessment and any risk reduction actions taken. This will be carried out by the data controller.
- ✓ Data may only be made available via a legally binding data agreement.

[UCLPartners](#), a partnership of world-leading academic and clinical research centres, NHS organisations, industry, patients and others, is the lead partner of DATA-CAN and a registered company (number 06878225). UCLPartners is the only partner through which the legal liabilities or obligations of DATA-CAN be incurred.

DATA-CAN operates through a [Management Group](#) (including two patient representatives) which meets formally monthly, as well as informally weekly. This Group reports, via the DATA-CAN Hub Director ([Dr Charlie Davie](#)), to the [Steering Board](#) (which also has two patient representatives as well as an independent Chair) and formally meets quarterly.

DATA-CAN will generate revenues both from the services it provides and from data controllers and services providers who may charge fees to end users (e.g. research institutions). DATA-CAN will not distribute any profits to partners, but they will be reinvested to help deliver the shared vision of the project. Any researcher wishing to access data provided by DATA-CAN will firstly need to demonstrate how their research will benefit patients and the NHS.