

# DATA SHARING AND MANAGEMENT POLICY

## 1 Purpose

This policy sets out Cancer Research UK's (CRUK's) position on data sharing and management.

At CRUK, we want to ensure the results of the research we fund maximise patient benefit. This includes creating an environment and culture that enables and incentivises researchers to maximise the value of their research outputs, including data, for reuse across sectors.

Our [Research Data Strategy](#) sets out how we will capitalise on our position as a leading funder of cancer research to maximise the reuse of research data and unleash its potential to beat cancer.

## 2 Scope

This policy applies to all researchers and their Host Institutions that submit grant applications to, or are funded by, CRUK. Researchers include, for example, CRUK grant applicants and grant holders, co-investigators, research staff and students.

We recognise that different fields of study will require different approaches so this policy does not prescribe how researchers should share and manage data, but we require them to make clear provision for doing so when planning and executing their research. See [CRUK's guidance](#) on best practice, commonly used repositories and how to decide which repository to use, including key criteria to consider such as the ability to place restrictions on commercial use/data access while retaining open access for academic research use.

This policy forms part of our grant conditions and sets out the requirements for researchers before, during and after their CRUK-funded research.

## 3 Definitions

**Cancer Research Horizons:** The trading name for Cancer Research Technology (CRT). CRT is a company registered in England & Wales No: 1626049 whose registered address is 2 Redman Place, London, E20 1JQ and wholly owned subsidiary of Cancer Research UK.

**DOI:** A Digital Object Identifier is used to uniquely identify and provide a permanent link to a digital object, such as a research dataset or journal paper.

**ORCID ID:** Open Researcher and Contributor IDs are unique and persistent individual identification numbers which are used to identify individual scientific contributors and authors, and to distinguish individual scientists from others.

## 4 Key Points

### 4.1 Our position on research data sharing and management

CRUK carries out world-class research to improve our understanding of cancer and find out how to prevent, diagnose and treat different kinds of cancer, working in partnership with others to achieve the greatest impact.

We recognise and encourage the dissemination of research outputs in all formats, including publications, preprints and other non-traditional research outputs (including, but not limited to datasets, software, methods, protocols and policy papers).

CRUK expects Host Institutions and all those involved in CRUK-funded research to abide by a culture of sharing research data for re-use across sectors. This culture nurtures good practice in which data sharing is an expected norm and is a central tenet of the leadership's vision of success and permeates the behaviours and practices of individuals at every level.

All those involved in CRUK-funded research are expected to make every effort to ensure that new studies that result from data sharing should meet the high standards of all CRUK-supported research regarding scientific quality, ethical requirements and value for money; new studies should also add recognisable value to the original dataset. Such research is often most fruitful when it is a collaboration between the new user and the original data creators or curators, with the responsibilities and rights of all parties agreed at the outset.

#### **4.1.1 Data sharing for academic non-commercial research purposes**

As a signatory to the [Concordat on Open Data](#), CRUK wishes to ensure that data arising from the research that it funds should be managed and made available to the academic community for academic non-commercial research purposes.

Data should be made available as widely and freely as possible to maximise public benefit, ensuring compliance with any applicable ethical requirements and while safeguarding the privacy of research participants, through following UK GDPR and relevant local rules and regulations.

#### **4.1.2 Data sharing for commercial purposes**

CRUK supports commercial data partnerships. If researchers believe their data is potentially proprietary and/or of commercial potential, they should contact Cancer Research Horizons at [horizons@cancer.org.uk](mailto:horizons@cancer.org.uk) for support in enabling commercial data sharing that is compatible with academic open access approaches outlined in this Policy and our [Guiding Principles for Data Partnerships](#).

It may be necessary on occasion to delay publication or restrict the release of data. Cancer Research Horizons at [horizons@cancer.org.uk](mailto:horizons@cancer.org.uk) can provide advice and support in filing patents and any other commercial opportunities that may not be aligned with this Policy.

## 4.2 Pre-research requirements

We regard it as essential practice for all researchers to consider at the grant application stage how they will manage and share the data they will generate.

When applying for funding, CRUK requires grant applicants to provide a data management and sharing plan (see [Guidance for researchers on writing data sharing plans](#)) as part of their application which aligns with FAIR (Findable, Accessible, Interoperable and Reusable) data principles and our Research Data Strategy. This plan will be reviewed as part of the funding decision.

CRUK's expectation is that all data will be shared appropriately, and support is available from CRUK to:

- facilitate the fair and transparent sharing of research data with commercial organisations in a governed/regulated manner.
- interpret this Policy and related guidance, e.g. [Writing data sharing plans](#).
- fund eligible costs relating to delivering the data sharing plan as part of funding the research according to our [Costs Guidance](#).

If the data arising from the grant application is not deemed to be suitable for sharing, applicants should discuss these reasons with the CRUK Research Data Strategy team ([researchdata@cancer.org.uk](mailto:researchdata@cancer.org.uk)), with a view to developing a data sharing plan that meets the needs of all those involved.

**Citation of datasets.** CRUK believes that data generators and sharers should receive full and appropriate recognition (e.g. by acknowledged

collaboration and/or citation) by funders, their academic institutions and new users for promoting secondary research. As a signatory to the [San Francisco Declaration on Research Assessment](#) (DORA), CRUK values the sharing of all types of research outputs, and we consider the value and impact of those outputs during our research assessment process. To acknowledge appropriate recognition of data generators and sharers, and allow appropriate citation of datasets, we require researchers to use persistent identifiers such as Digital Object Identifiers (DOIs) for datasets and Open Researcher and Contributor IDs (ORCID IDs) for researchers and use those IDs when referencing datasets (e.g. in relevant sections of the grant application forms).

**Data standards.** CRUK recommends using common data standards to facilitate the reuse of research data as per our [Data Sharing Guidelines](#).

**Data diversity.** For research data to have the greatest utility when re-used, as well as having been generated using reproducible methods, according to commonly used data standards and associated with high quality metadata, CRUK encourages researchers to work toward building datasets derived from diverse groups of people and reflect that diversity in the metadata.

**Patient consent:** Researchers must confirm in their grant application that patient consent forms will include detail around the future intention to share data and samples with academic, commercial and third-party partners for secondary purpose research where relevant. CRUK wants to ensure samples and data arising from CRUK-funded research are made available to the wider cancer research community in a usable form. If you foresee any issue with this, please contact [researchdata@cancer.org.uk](mailto:researchdata@cancer.org.uk) to discuss.

## 4.3 Research requirements

Throughout any research supported by CRUK, CRUK requires researchers to:

- report datasets generated as part of existing reporting arrangements e.g. by listing them in the “Research Datasets, Databases & Models” Researchfish category, including detail on how the datasets were made findable and accessible for re-use to both academics and, in collaboration with Cancer Research Horizons, commercial organisations.
- curate data arising from CRUK-funded research properly throughout its lifecycle and released with the appropriate high-quality metadata in order to make stored data FAIR (Findable, Accessible, Interoperable and Reusable) in a manner appropriate to the discipline and/or the methodology that was used to produce the data. This is the responsibility of the data custodians – those individuals or Host Institutions that are recipients of CRUK funding – to create or collect the data.
- notify and discuss further with [researchdata@cancer.org.uk](mailto:researchdata@cancer.org.uk) where publication in a journal or submission to a database/registry would result in data access being inconsistent with this Policy.

#### **4.4 Post-research requirements**

CRUK-funded researchers must:

- **release data:** no later than the acceptance for publication of the main findings from the final dataset (unless restrictions from third party agreements or IP protection still apply) or on a timescale in line with the procedures of the relevant research area. Researchers providing and receiving data are required to adhere to any relevant regulatory requirements including those relating to the ethical use of data. Access requests for commercial use or from commercial organisations will be dealt with separately on commercial terms and subject to any pre-existing arrangements. Commercial data partnerships must align with Cancer Research Horizons’ Guiding Principles on Data Partnerships to ensure fairness, transparency and involvement of people affected by cancer where patient data is

involved. Cancer Research UK's Commercial Partnerships team can provide advice with regard to dealing with such requests.

- **use a data access statement** that clearly outlines how data can be accessed and any differences between academic and commercial access guidance on developing appropriate data access statements.
- **give appropriate recognition of contributions** to those who are involved in generating, collating, linking and analysing data. Adequate and permanent references (for example [Contributor Roles Taxonomy \(CRediT\)](#) statements) must be provided in publications to increase the visibility and recognition of all those involved.
- **give appropriate recognition of patient-derived data** in project outcomes using [Use MY data citation](#).

## 4.5 Monitoring by CRUK

CRUK may carry out ongoing monitoring to ensure data sharing and management for CRUK-funded research projects are in line with the requirements outlined in this Policy.

## 5 Support & Advice

For any queries about this policy please contact:

- Research data strategy: [researchdata@cancer.org.uk](mailto:researchdata@cancer.org.uk)
- Cancer Research Horizons: [horizons@cancer.org.uk](mailto:horizons@cancer.org.uk) (for queries on commercial use of research data)

## 6 Related documents

For more information, please see the following linked documents:

- [CRUK's Conditions of your Grant](#)
- [CRUK's Research Integrity: Guidelines for Research Conduct](#)
- [Commercial Partnerships website](#)
- [Cancer Research Horizons Guiding Principles for Data Partnerships](#)

<b>Policy sponsor</b>	Dr Iain Foulkes, Executive Director of Research & Innovation, CEO Cancer Research Horizons
<b>Policy owner</b>	Dan Burkwood, Director of Research Operations and Communications
<b>Subject Matter Experts (SME)</b>	Research Data
<b>Executive Board or Council approval required?</b>	No – approved by Grants Management Policy Board
<b>Date of last review</b>	February 2025
<b>Next review due</b>	February 2028
<b>Superseded documents</b>	Version 7

Key changes to the policy should be recorded below:

<b>Version</b>	<b>Date</b>	<b>Author</b>	<b>Approved by</b>	<b>Summary of changes</b>
7	25/2/25	Leslie Glass	GMPB	<ul style="list-style-type: none"> <li>- New patient consent requirements added to section 4.2</li> <li>- New appropriate recognition of contributions added to section 4.4</li> <li>- New monitoring by CRUK section 4.5 added</li> </ul>