

# Cancer Research UK (CRUK): Population Research Committee Template

## 0. Title of project/programme

State the title of the project/programme

*Guidance:*

As named in eGMS

## 1. Description of the data

### 1.1 Type of study

*Guidance:*

Up to three lines of text that summarise the type of study (or studies) for which the data are being collected.

### 1.2 Types of data

*Guidance:*

Types of research data to be managed in the following terms: quantitative, qualitative; generated from surveys, clinical measurements, interviews, medical records, electronic health records, administrative records, genotypic data, images, tissue samples etc.

### 1.3 Format and scale of the data

*Guidance:*

File formats, software used, number of records, databases, sweeps, repetitions,... (in terms that are meaningful in your field of research). Do formats and software enable sharing and long-term validity of data?

## 2. Data management, documentation and curation

### 2.1 Managing, storing and curating data

*Guidance:*

Briefly, how data will be stored, backed-up, managed and curated in the short to medium term. Specify any community agreed or other formal data standards used (with URL references). [Enter data security standards in Section 3].

### 2.2 Metadata standards and data documentation

*Guidance:*

Plans for documenting, annotating and describing data so that research data are usable by others than your own team. This may include documenting the methods used to generate the data, analytical and procedural information, capturing instrument metadata alongside data, documenting provenance of data and their coding, detailed descriptions for variables, records, etc.

### 2.3 Data preservation strategy and standards

*Guidance:*

Plans and place for long-term storage, preservation and planned retention period for the research data. Formal preservation standards, if any. Indicate which data may not be retained (if any).

### **3. Data security and confidentiality of potentially disclosive personal information**

#### 3.1 Main risks to data security

*Guidance:*

If not using formal standards, summarise the main risks to the confidentiality and security of information related to human participants, and how these risks will be managed. Cover the main processes or facilities for storage and processing of personal data, data access, with controls put in place and any auditing of user compliance with consent and security conditions.

### **4. Data sharing and access**

#### 4.1 Mechanisms for sharing

*Guidance:*

Data generated across all research areas has the potential for re-use and should be shared regardless of whether they have been used in a publication. Use this section to identify any data repository (-ies) that are, or will be, entrusted with storing, curating and/or sharing data from your study, where they exist for particular disciplinary domains or data types.

Consider:

- Personal data relating to human participants in research
- Intellectual property rights and proprietary data

#### 4.2 Discovery by potential users of the research data

*Guidance:*

Indicate how potential new users can find out about your data and identify whether they could be suitable for their research purposes, e.g. through summary information (metadata) being readily available on the study website, or in other databases or catalogues.

Indicate whether your policy or approach to data sharing is (or will be) published on your study website (or by other means).

#### 4.3 The study team's exclusive use of the data

*Guidance:*

CRUK's requirement is for timely data sharing, with the understanding that a limited, defined period of exclusive use of data for primary research is reasonable according to the nature and value of the data, and that this restriction on sharing should be based on simple, clear principles. Summarize the principles of your current/intended policy.

#### 4.4 Restrictions or delays to sharing, with planned actions to limit such restrictions

*Guidance:*

Restriction to data sharing may be due to participant confidentiality, consent agreements or IPR. Strategies to limit restrictions may include data being anonymised or aggregated; gaining participant consent for data sharing; gaining copyright permissions. For prospective studies, consent procedures should include provision for data sharing to maximise the value of the data for wider research use, while providing adequate safeguards for participants. As part of the consent process, proposed procedures for data sharing should be set out clearly and current and potential future risks associated with this explained to research participants.

#### 4.5 Milestones for sharing

*Guidance:*

Detail major milestones in your plans for sharing. This can be recorded in yearly intervals and can include expected times of publications. This will be used to track your progress towards data outputs and sharing as collected annually in Researchfish.

#### 4.6 Governance of access

*Guidance:*

Identify **who** makes or will make the decision on whether to supply research data to a potential new user, and indicate how independent oversight of data access and sharing works (or will work). Include details of the person to contact for potential new users to request data (unless plans involve submission of data to a third party repository).

#### 4.7 Regulation of responsibilities of users

*Guidance:*

Indicate whether external users are (will be) bound by data sharing agreements, setting out their main responsibilities.

### **5. Responsibilities**

#### 5.1 Outline responsibilities for data management

*Guidance:*

Specify who, alongside the PI, is responsible for ensuring the study-wide data management, as well as for specific roles such as metadata creation, data security and quality assurance of data.

### **6. Relevant institutional, departmental or study policies on data sharing and data security**

6.1 Please complete, where such policies are (i) relevant to your study, and (ii) are in the public domain, e.g. accessibly through the internet. Add any others that are relevant.

### **7. Author and contact details**

7.1 Author of this Data Management Plan (Name) and, if different to that of the Principal Investigator, their telephone & email contact details