

UKCRC Tissue Directory and Coordination Centre

Principles for Transparency

Definitions

- Primary Source – The organisation that has contact with donors, takes the consent and collects the samples at source. This would most likely be a biobank in an academic or NHS institution.
- End User – The research group (academic or commercial) that will be utilising the samples or data in a research project.
- Access Organisation – The organisation that provides a service or platform for the End-User to acquire samples from the Primary Source. This would most likely be a commercial entity that provides a chargeable service to find samples and data from academic or NHS biobanks.

Background

Patients have donated valuable sample and data resources to biobanks in the UK, yet, researchers state that finding and accessing samples is a challenge. Specific public and private organisations now exist to help researchers to find, access and use samples in their research. These Access Organisations operate with different transparency policies, which can cause challenges in how patients and Primary Sources (biobanks) are informed about the use of samples. These differences in transparency policies also affect when biobanks can or cannot be cited in publications. Researchers, or End Users, use these citations as a key way to identify suitable biobanks for their research so it is an important step in maximising value.

The Tissue Directory and Coordination Centre (TDCC) is seeking to outline transparency principles that guide how these Access Organisations operate in relation to the sharing of information between parties. These principles are independent of their business model. We are searching for sample and data access organisations to commit to these voluntary principles to promote transparency.

Principles

The Primary Source shall:

- 1) Always know both the End User and the intended use of the samples and/or data and make this available to donors on request

The Access Organisation shall:

- 1) Pass on any End User feedback on the suitability and appropriateness of the samples or data supplied by the Primary Source
- 2) Always pass on the details of the Primary Source to the End User when the End User is publishing (literature or patent).

The End User shall:

- 1) Be able to obtain the details (name, contact details) of the Primary Source from the Access Organisation if felt necessary by the End User
- 2) Commit to acknowledge and cite the Primary Source in any publication (literature or patent)