



Confederation of Cancer Biobanks (CCB) Executive Group: Terms of Reference

CCB Background Information

The CCB was formed in 2006 as a networked consortium of independently managed and autonomous organisations in the UK involved in the development, management and use of biosample resources for cancer research. The main aims of the CCB are to promote and disseminate a collective view on best practices for Biobanks, which will drive harmonisation and promote transfer of knowledge among banks.

From 2011, the CCB Secretariat is being supported through the NCRI Secretariat, under the governance of the NCRI Board who have asked for additional work to be undertaken to explore the feasibility of a quality benchmarking scheme for biosamples used in cancer research and for an expansion of the CCB to become more fully representative of the cancer biobanking community in the UK. Sample collectors who do not necessarily see their collections as “biobanks” will be encouraged to join.

All CCB activities are now to be taken forward within the framework set out in the UK Funders’ Vision for Human Tissue Resources’ published in September 2011 (<http://www.ukcrc.org/infrastructure/expmed/fundersvisionforhumantissuesresources/>). The essence of the Vision is that *‘Funders aim to maximise the value of human tissue samples and resources while minimising duplication of effort. This requires better characterisation of tissue samples, asking for generic consent, and increased linkage to accurate clinical data. Sample collections must then be made more easily discoverable and accessible for use in high quality, ethical, research’*.

Purpose of CCB Executive Group

An enlarged Confederation needs a smaller group to guide activities, plan events and make operational decisions. It will also help to develop the CCB as a representative body by seeking members’ opinions internally and reflecting them externally. It will ensure that the CCB works within the strategic context of the Funders’ Vision. Members do not just attend meetings but are actively involved in taking forward actions between meetings.

Activities of the CCB Executive Group (CCB EG)

The CCB EG will work closely with the CCB Secretariat in the following activities and in determining for itself the most appropriate working methods to deliver results. Activities include:

- Developing and implementing a recruitment plan to define and communicate the incentives for, and benefits of, CCB membership with a view to expanding membership substantially.
- Planning workshops on defined topics as well as supporting open-forum meetings to gather broader opinion, particularly in areas of best practice and harmonisation.
- Enabling the CCB to act as an independent voice for cancer biobanking; for example in response to public consultations on regulatory, ethical and quality issues.

- Ensuring that all CCB documents are compliant with the Funders' Vision and engaging with funders on any issues arising.
- Acting as a sounding board for the CCB secretariat especially in relation to the benchmarking project.
- Advising the CCB Secretariat in the preparation of annual workplans and budgets for the NCRI Board.
- Developing best practice consensus statements via workshops and/or working groups.

Responsibilities of Executive Group Members

- To act as advocates for the CCB and uphold/promulgate the Confederation's Guiding Principles.
- To attend and contribute regularly to meetings, teleconferences and correspondence, as needed.
- To undertake agreed actions between meetings and/or lead working groups on behalf of the Executive Group.
- To be aware of the work of the wider biobanking community, including other disease areas and the international environment.
- To support the engagement of biosample donors in the research effort, in so far as resources allow.

Membership

The Executive Group comprises:

- Chairperson
- Member Biobank Representatives (5/6)
- Consumer member
- Director of NCRI
- Pathology Leads for NCRI

Frequency of Meetings

It is anticipated that the CCB EG will require at least two face-to-face half-day meetings per year plus additional interim teleconferences. Frequency of meetings and teleconferences will be monitored and reviewed at the end of each year.

Support and Resource

The CCB EG will be supported by up to 2 FTE staff from the NCRI Secretariat who will arrange meetings and teleconferences, develop agendas and minutes from meetings and also undertake specific agreed actions from meetings.

Accountability

The CCB EG will report to the NCRI Board on the work of the CCB

Period of Tenure

Tenure of 2 years is anticipated in the first instance but this will be reviewed after the first year of the Group's operation, at the same time as the terms of reference. New member biobank representatives will be introduced in a staggered manner to ensure continuity.

Date: 1st March 2013

Terms of reference to be reviewed in early 2014.