

Memorandum of understanding between the independent organisations constituting the Members of the Confederation of Cancer Biobanks

A DEFINITION

1. The Confederation of Cancer Biobanks (“CCB”) is a consortium of organisations based in the United Kingdom that are involved in the development, management and use of Biobank resources for cancer research. Constituent organisations of the CCB will be known as “Members”.

B. INTRODUCTION:

1. Collection, annotation and subsequent use of human biosamples (in Biobanks) are essential parts of cancer research. Biobanking is an activity that contributes to the possibility that preventative measures be found, that future patients may access novel therapies and that novel pathology and molecular based diagnostic and prognostic services may be developed.
2. Biobanks are service providers for repositories of living cells, genomes of organisms, of preserved cells and tissues, and of information relating to these materials. Developing and managing a Biobank requires adherence to strict technical requirements and has far-reaching legal and ethical implications. Biobanks are subject to conventions and sets of regulations at organisational, local, national and international levels. Members may or may not be legal entities in their own right. The Confederation itself is not a legal entity, it is managed by the Members, with the assistance of the NCRI Secretariat, for the Members’ benefit.
3. Networking between Biobanks is essential for many aspects of cancer research, including multi-centre cohort studies and clinical trials, studies on rare pathologies, and comparative studies aimed at assessing the aetiological, pathological and genetic heterogeneity of common cancers. Biobanks are rapidly becoming the cornerstone of translational approaches in molecular medicine.
4. The CCB is a networked consortium of independently managed and autonomous organisations involved in the development, management and use of the biosample resources for cancer research. Formed initially by a small number of representatives from tumour banks in the UK, the intention is to be inclusive and to build from this nucleus. The CCB is open to organisations involved in the management of Biobanks that are willing and able to, or aspire to, work to the commonly agreed principles and practices endorsed by the members of the Confederation.

C OBJECTIVES

1. The objectives of the CCB are to promote and disseminate consensus on best practices for Biobanks, to assist in Biobank development by providing advice and mutual support, and to promote networking between Biobanks by developing procedures and practices that facilitate the sharing of resources. In pursuit of these objectives, a major preoccupation of the CCB will be the promotion of consensual standards acceptable and applicable in Biobanks of different organisations, including the transfer of know-how, experience and technologies between Biobanks. While individual Biobanks retain their full autonomy, the Confederation’s vision is to work towards a seamless operation so that sample users experience what appears to be a single virtual Biobank for the collection and distribution of biosamples for cancer research.

D MEMBERSHIP:

1. Members of the CCB are organisations involved in activities as defined above and not individual scientists or other professionals. Members expect to share with the consortium their expertise, ideas and non-financial resources, including protocols, methods, results, raw data, and, when agreed appropriate, biological samples.
2. Membership of the CCB is open to organisations managing cancer Biobanks that are willing and able to, or aspire to, work to the commonly agreed principles and practice endorsed by the Members of the Confederation. New members are expected to meet the agreed benchmarks and standards that all founder members adhere to.
 - a. In particular, Members agree to work in pursuit of commonly agreed and achievable standards for the quality for biosamples to achieve aggregate resources that are fit for a variety of scientific purposes.
 - b. Members will be encouraged to share technologies where appropriate and to foster convergence of common standards for infrastructure and methodologies.
3. Members agree to work to the spirit of the common Guiding Principles for the operation and management of human research biobanks, as adopted by the Members and as published periodically by the Secretariat. The Guiding Principles is a live document that will be subject to change and D3 refers to the most recent version in publication at that time.

E RESOURCES:

The CCB has no dedicated resources. Organisations participating in the collaboration do so at their own cost, and are encouraged to provide a minimal amount of resources, e.g. by contributing to the organisation of meetings and the coordination of working groups. Members may raise ad-hoc funds to support administration, coordination, meetings or the specific activities of working groups or individual Members. The NCRI Secretariat may assist the CCB where necessary or appropriate to the running of the CCB and its initiatives.

F MUTUAL BENEFIT AND INTERESTS:

1. The CCB will benefit all Members involved by fostering the sharing of expertise and information and the establishment of harmonised operating procedures within Biobanks, so as to avoid unnecessary duplication.
2. The research effort against cancer, and through this cancer patients, will benefit from the provision of a unified route for access by cancer researchers to an aggregate resource of biosamples from the confederated banks.
3. The CCB will also provide assurance to organisations funding cancer research that resources are being managed in a consistent and effective manner.

G DIFFERENT COMMUNITIES, ONE APPROACH:

Members will have mutual respect for each partner's position within the wider stakeholder environment; which will include each retaining its own identity and autonomy of decision-making. Members will work actively together with the intention that this will lead to a more rapid harmonisation of practices than would otherwise be possible. Such harmonised practices

will be based on agreed principles. The operational application of the agreed principles will be for each Member to determine, according to the needs of their individual organisations. Objectives will include:

1. to identify opportunities to improve services and / or supply of cancer biosamples.
2. to develop a harmonised approach to the acquisition, storage and distribution of cancer biosamples.
3. to agree upon common ethical and legal principles and policies to guide the operation of member Biobanks.
4. to agree principles that should govern access to resources.
5. to actively pursue the co-development of a common IT (web-based) portal for researchers seeking access to samples.
6. to look for new ways to work together when it will add value to do so.
7. to share resources and information to avoid duplication of effort and unnecessary competition that may damage partner Members.
8. to broaden the Membership of the Confederation to make it both more inclusive and more influential.
9. to assist NCRI in the development of an accreditation scheme that will define standards, may be used as a mechanism to maintain and gain membership of the CCB and that will be aligned and compatible with other developing international standards applicable to human research biobanks.

Members of The Confederation may mutually agree priorities, targets and timescales amongst these objectives, and any others they deem appropriate.

H OTHER PROVISIONS:

1. Modifications of the scope and content of this Memorandum shall be made by mutual consent of the Members.
2. This Memorandum in no way restricts members of the CCB from participating in similar activities with other public or private agencies, organisations, and individuals, as long as doing so is not deemed by the majority of Members as incompatible with membership of this Confederation.
3. Any of the Members, as notified in writing to all other members, may terminate their Membership of the CCB at any time. The CCB will survive such resignations unless there are fewer than 2 active Members at any one time.
4. This Memorandum does not confer fiscal or funding obligations between the Members. Any endeavour or transfer of anything of value involving reimbursement or contribution of funds between the Members of the CCB will be handled in accordance with applicable laws, regulations, and procedures, including those for Government procurement as appropriate. Such endeavours will be the subject of separate agreements that shall be made in writing by representatives of the relevant parties and shall be independently authorised by the appropriate statutory authority. This Memorandum does not provide such authority.