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[www.ncri.org.uk/ccb](http://www.ncri.org.uk/ccb)

# CCB Update

Issue 6, June 2012

### Note from the Editor

*Caroline Magee, Communications Lead, NCRI (CCB Secretariat)*

Welcome to this issue of CCB Update – the newsletter from the National Cancer Research Institute's Confederation of Cancer Biobanks (CCB).

The CCB Executive Group has been busy over the past few months and we are pleased to bring you news of new membership categories for the CCB as well as a report from our first member-hosted meeting.

We have a report from the LLR Childhood Leukaemia Cell Bank on the centralisation of their bank and details of a new e-learning module from MRC on regulatory aspects of accessing data for research to complement their resource on tissues.

To provide feedback on the newsletter, please contact [ccb@ncri.org.uk](mailto:ccb@ncri.org.uk)

## CCB Member-hosted meeting series off to a flying start

The first of a new series of member-hosted meetings was held at Guy's Hospital in early May on the topic of **Biosample Quality**. The programme was developed by the biobanks at Guy's & St Thomas' Research Tissue & Data Bank and King's College London Haemato-oncology Tissue Bank and chaired by Dr Bridget Wilkins, Consultant Haematopathologist at Guy's and NCRI Pathology Lead for NHS Engagement in Biobanking.



Speakers and facilitators at the Symposium on Biosample Quality

The event proved very popular and was over-subscribed within a few weeks of registration opening. Around 60 delegates heard presentations from the host biobanks as well as talks from Dr Daniel Grözl of Qiagen on the European SPIDIA project and Anne Carter of CCB on

sample fitness for purpose. The speakers' presentations can be accessed via the CCB website.

Feedback on the event was highly positive with 88% of delegates rating the event as excellent or very good. We also received some really useful suggestions for future topics for these meetings.

The next event will cover **Access and Consent** and is being hosted by CCB Member Newcastle Biomedicine Biobank in the autumn. Registration will open in July and further details will be posted on the events page of the CCB website ([www.ncri.org.uk/ccb/upcomingevents.html](http://www.ncri.org.uk/ccb/upcomingevents.html))

## New Membership Categories for CCB

To help ensure that the CCB becomes more fully representative of the cancer biobanking community in the UK we have introduced new membership categories.

For biobanks these are Member and Provisional Member. Members must fulfil the following criteria:

- Currently providing samples for cancer research to any researchers with bona fide projects (at least in the UK)
- Compliant with **CCB Guiding Principles**
- Sample collection is discoverable by researchers (listed in the **NCRI Cancer Biosample Directory** as a minimum)

Provisional members are those biobanks that are working towards fulfilling the criteria.

We are also introducing a category of 'Registered Collection' that will be open to investigators holding biosample collections where there is an intention to allow wider research use of the samples in the longer term, following the initial primary research use. This category would include collections developed as part of a variety of study types, including clinical trials and would help increase the visibility of the collection and potential for future research collaborations.

This aligns with the aims of the **UK Funders' Vision for Human Tissue Resources** to maximise the value of collections and minimise duplication of effort.

## Redeveloped NCRI Biosample Directory goes live

The NCRI Biosample Directory has been redeveloped and now has its own website. The user interface has also been improved.

The directory provides a route for cancer researchers to find the samples they need for their research and the new site should be easier to use. The directory can be searched for cancer biosamples held in both biobank(s) and clinical trial collections in the UK.

Information is included about access arrangements and how to contact custodians.

The aim is for the majority of cancer biosample collections in the UK to be included in the directory and we are calling for more biobanks and sample collections to list their details on the directory.

View the directory at <http://biosampledirectory.ncri.org.uk>

### NCRI Cancer Biosample Directory

[Home](#) [Advanced search](#) [About](#) [For custodians](#)



### Search biosample collections

This directory provides a route for cancer researchers to find the samples they need for their research. The aim is for the majority of cancer biosample collections in the UK to be included in the directory.

The directory can be searched for cancer biosamples held in both biobank and clinical trial collections in the UK. Information is included about how access may be possible and how to contact custodians.

Collections are listed below and may be filtered based on name or tissue type. An [advanced search](#) is also available.

Collection name/tissue type:  Collection type:  Biobank  Clinical trial

#### Biobanks

Name ▲	Access status
<a href="#">Breast cancer AC DNA collection</a> Tissue types: Breast	Other
<a href="#">Breast Cancer Campaign Tissue Bank</a> Tissue types: Breast	Open to applicants

## Leukaemia & Lymphoma Research Childhood Leukaemia Cell Bank: A centralised bank for all childhood leukaemia samples.

### Anne Thomson, Manager of the LLR Cell Bank provides an overview of the recent changes to and expansion of the bank.

The Leukaemia & Lymphoma Research (LLR) Childhood Leukaemia Cell Bank was originally formed as a repository for samples left over after diagnostic MRD (minimal residual disease) tests on bone marrow samples from children enrolled on the national ALL2003 clinical trial. These were stored as viable cells and DNA by the four MRD labs performing diagnostic tests for the trial, thus forming a 'virtual' bank. Samples for peer-reviewed research have been released since 2007, resulting in high quality publications and incorporation of translational research into clinical trials and guidelines. By 2009 the success of the bank meant that the capacity of the MRD labs was reaching critical point and changes were needed.

Catalysed by the completion of the recruitment phase of ALL2003 and the start of ALL2011, following competitive tendering and independent peer-review, the Cell Bank was centralised and relocated to the state of the art facilities at UK Biocentre, a wholly owned subsidiary of UK Biobank with expertise in biobanking. This was generously funded by a feasibility grant from LLR and has been funded for a further 3 years.

Cell Bank currently holds over 45,000 retrospective samples of viable cells and DNA from ALL2003 and other national childhood leukaemia trials which are available for research by application to the Cell Bank. Applications are reviewed by a newly formed Cell Bank Application Review panel (CBAR). This provides rapid, independent, expert review of applications.

Samples are provided with a basic data set comprising sex, age at diagnosis, immunophenotype, cytogenetics and white cell count. Samples for approved research projects are available free of charge, the only costs incurred being packaging and delivery.

Generous funding from LLR has allowed expansion of the samples banked to

include not only trial patients, but also those not involved in clinical trials. Cell Bank collects samples of bone marrow, peripheral blood and CSF taken (with informed consent) specifically for banking at the same time as diagnostic samples. Excess samples from diagnostic tests are also banked. Broadening the remit of Cell Bank to include all paediatric leukaemia patients facilitates collection of samples where there is no clinical trial and, by providing a central repository, supports research into some of the rarer forms of leukaemia.

We are very grateful to all the families, doctors, nurses and laboratory staff at the clinical centres who make Cell Bank possible.

Further information on the LLR Childhood Leukaemia Cell Bank and details of how to apply for samples can be found on the website: [www.cellbank.org.uk](http://www.cellbank.org.uk) or by contacting Cell Bank (e-mail: [cellbank@egu.york.ac.uk](mailto:cellbank@egu.york.ac.uk), tel: 01904 321880)



### Research Data and Confidentiality: New e-learning module

This new module is designed for researchers, data managers and others. It provides the tools needed to navigate the duty of confidence, data protection legislation and other rules governing access to health data, with confidence. The module uses real life examples to consolidate learning in what is very complex and confusing field.

It has been developed by the MRC Regulatory Support Centre with input from regulators and investigators; and joins their growing portfolio of e-learning modules, which are available to everyone from [www.mrc.ac.uk/regulatorysupportcentre](http://www.mrc.ac.uk/regulatorysupportcentre)

*"easy to navigate... a really useful tool which I'll be pushing to our researchers"*

Imperial College  
London



*"tremendous job with a dauntingly large and difficult subject"*

Health Research  
Authority

Find it at: [www.mrc.ac.uk/regulatorysupportcentre](http://www.mrc.ac.uk/regulatorysupportcentre)



## Getting to know you: Maggie Wilcox, Lay Member of CCB's Executive Group

Maggie Wilcox is a retired Health Visitor and, having been treated for breast cancer, became a lay member of the NCRI Breast Clinical Studies Group and is a founder member of the charity Independent Cancer Patients Voice (ICPV). She is also a lay member of the Board for the Breast Cancer Campaign Tissue Bank, helping to ensure that patient benefit remains the priority aim of this project.

### What's the most enjoyable/satisfying part of your job?

Reassuring professionals that most people are very happy to be approached about donating tissue and assisting research.

### What are you doing to help the engagement with potential tissue donors?

ICPV has produced a patient information leaflet about involvement in cancer research and treatment/service development. We have adapted this for specific use with Breast Cancer Campaign in providing information about the value of donating to the Breast Tissue Bank

### What challenges/issues for potential donors need to be addressed by the biobanking community?

There will be increasing public knowledge and interest in biobanking which will probably lead to more questions – many of which will be more complex. Tissue banks are going to have to listen to what the donors want in terms of information – especially in terms of feedback of results.

### What misperceptions do you think there are of patients/donors' views of use of tissue for research?

That patients are not able to cope with being asked to donate at a time when they are already stressed. That teenagers and young adults are not able to make informed decisions about donating. That donors are not interested in what happens to donated tissue.

### What's your prediction for the future for tissue banking in the UK?

It is the future and will need to have increased PPI and this needs to be effective – ie ensure proper education, mentoring and funding is provided for lay members so that they are well informed and confident in discussions with professionals.

### What's the best feedback you've had as a lay research member?

This quote from the Chair of the Breast Cancer Campaign Tissue Bank: "The 2 lay members have kept us grounded in reality and have been very helpful in ethics and patient information issues. They made us realise standard practice is a terrible waste of resources – throwing away tissue which could be valuable in research. It has been a real pleasure working with them."

### What's the most useful thing you've learnt from your tissue banking colleagues in the CCB network?

Not to worry that my question might be daft – it might be very relevant and obvious but has been missed. The "elephant in the room" question!

### Which words or phrases do you most overuse?

Dry white, please!

### How do you relax?

I am a member of a local gym, NADFAS, wine-tasting group and an arts charity.



To provide feedback on this newsletter or to contribute articles please email us at [ccb@ncri.org.uk](mailto:ccb@ncri.org.uk)