Confederation of Cancer Biobanks

CCB Update

Issue 8, December 2013

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www.ncri.org.uk/ccb

Note from the CCB Secretariat

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

We have a feature on patient involvement in biobanking and updates on the progress of data standardisation in biobanking and establishment of a European biobanking infrastructure. We report on three recent CCB events and get to know Ekaterini Blaveri who is taking over support of CCB secretariat and leading on NCRI's biobanking activity.

To provide feedback on the newsletter, please contact ccb@ncri.org.uk

Three Day Eventing

The early part of November saw 3 CCB events in 8 days with two workshops at the NCRI Cancer Conference in Liverpool and our first public engagement event the following week. Here is a short summary of each of them.

Guiding Researchers

This 90 minute workshop on the Monday afternoon of the NCRI Cancer Conference provided an opportunity for CCB to raise awareness with researchers of the key points to consider when using samples for a research project. Manuel Salto-Tellez of Queen's University Belfast provided an insight into what funders often look for when reviewing grant applications that involve use of samples – which are becoming more common. Regulatory aspects and an introduction to accessing the pathology diagnostic archive for research were reviewed by Bridget Wilkins. Ian Forgie of Tayside Tissue Bank then took the audience through the steps involved in accessing tissue samples and how working with a tissue bank can help provide the correct type and format of tissue for the research. The session was rounded off by NCRI's Anne Carter who reviewed the main aspects of ensuring that tissue samples are fit for the research purpose and indicated how the NCRI's Biobanking Harmonisation project aims to help improve sample quality across biobanks.

2014 Events

Wales Cancer Bank will be hosting the next member-hosted event on June 18th in Cardiff. The topic will be patient/public engagement. Northern Ireland Biobank is also planning a meeting for the autumn.

Further details will be posted on the CCB website as they are confirmed. (www.ncri.org.uk/ccb/events)

NIBiobank Northern Ireland Biobank

Wales Cancer Bank Banc Canser Cymru

View the speakers' presentations on the CCB website http://www.ncri.org.uk/ccb/previousevents.html

Ensuring Success in Sample Collection in Clinical Trials

This half-day workshop was held immediately after the closing of the NCRI Cancer Conference and attracted around 80 delegates, of which around a half were conference delegates. The workshop was organised in association with the Liverpool GCLP and UK CLL Trials Biobanks. Bill Greenhalf of the GCLP Biobank chaired the meeting and also gave a presentation. The programme focused on several key challenges of sample collection as part of clinical trials with presentations covering

- Regulatory aspects both for the samples and the clinical trial
- Standardisation and Quality Issues in pathology and TMAs
- Future-proofing tissue collection against development of new technologies

This was followed by an interactive panel discussion on the future use of samples with panel members including representatives of funders, industry, patients and fundraising staff

The speakers' presentations from this workshop can be viewed on the CCB website
http://www.ncri.org.uk/ccb/previousevents.html

Engaging the public

This evening event - held on Monday 11th November - was CCB's first foray into public engagement and was masterminded by Bridget Wilkins, NCRI Pathology Lead. It was organised in collaboration with the Royal College of Pathologists and held at their venue in Pall Mall, London. The main feature was a debate of the concept of an interactive swipe-card as a tool to increase public engagement with the consent processes required for such donations.

Derek Stewart and Maggie Wilcox, joined Bridget Wilkins in providing a brief introductory presentation about pathology and the uses of tissue in research. They emphasised the strong public support for using surplus tissue from medical procedures for research - and the disappointment that can arise from not being asked.

All of our London-based member biobanks participated and provided a variety of interactive displays demonstrating aspects of diagnostic histopathology, tissue micro-array (TMA) construction, biobank operation and research arising from biobanked samples. Advocacy group Independent Cancer Patients' Voice (ICPV) also raised awareness of patient involvement in tissue-related aspects of research.

Science broadcaster Vivienne Parry generously donated her time to chair the main debate and added a lively commentary to the discussion that followed. Bridget Wilkins proposed the concept and NCRI Pathology Lead, Andy Hall provided a robust opposing argument. When the final votes were counted the audience gave their overwhelming support for the swipe-card scheme, despite its current impracticality.

Feedback from the event has been overwhelmingly positive with 94% of attendees stating that they found the event very interesting and enjoyable and we hope to run a similar event again in the future.

Anne Carter, NCRI Biobanking Portfolio Lead reports back from the BBMRI-ERIC Inauguration Conference held in Graz, Austria in September.

BBMRI-ERIC
Biobanking and
BioMolecular Resources
Research Infrastructure

The Biobanking and Biomolecular Resources Research Infrastructure (BBMRI) began as an FP7 funded project, with the preparatory phase of the project receiving €5 million in funding to prepare for the construction of a pan-European biobanking infrastructure. Since 2011 the preparation for the creation of a legal entity, BBMRI-ERIC (http://bbmri-eric.eu/), has been progressing and it received approval from the EC in November 2013. This allows it to be fully recognised with "legal personality and full legal capacity" in all EU Member States. The co-ordinating centre will be based in Graz, Austria and Jan-Eric Litton, from the Karolinska Institutet, has been appointed as the first Director-General (DG). BBMRI-ERIC has ten founding members and four observer countries (see box). Members provide input into the management of BBMRI-ERIC through a national co-ordinating centre (national node) whose Director reports to the DG.

Common Services

BBMRI-ERIC will provide Common Services to members. These include:

- biobanking and resource services
- IT services
- technology and reagent services
- service for quality management (to be hosted in Graz)
- services for ethical, legal and societal issues, and
- a stakeholder forum secretariat.

Common Services will be commissioned through a series of calls for proposals; only members will be able to respond to these calls. Common Services will be funded jointly by BBMRI-ERIC and the Member State in which the Common Service is located. The provision of Common Services maps to most of the actions outlined in the UK Funders' Vision[1]. In particular, development of a database of available samples and data, provision of access to this information through a web-based portal, integration of data from disease registries, harmonisation of procedures, definition of "good practice" requirements and accreditation of biobanks match well with current efforts in the UK.

These themes and the associated Common Services are described further in the latest version of the BBMRI-ERIC Business Plan (available here: (http://bbmri-eric.eu/downloads).

Benefits of membership

BBMRI-ERIC state that they will increase efficacy and excellence of European bio-medical research:

- by facilitating access to quality-defined human health/disease-relevant biological resources including associated data in an efficient and ethically and legally compliant manner,
- by reducing the fragmentation of the biomedical research landscape through harmonization of procedures, implementation of common standards and fostering high-level collaboration,
- by capacity building in countries with less developed biobanking communities thereby contributing to Europe's cohesion policy and strengthening the European Research Area.

BBMRI-ERIC Member and Observer organisations

Members	Observers
Austria	Norway
Belgium	Poland
Czech Republic	Switzerland
Estonia	Turkey
France	
Germany	
Greece	
Malta	
The Netherlands	

What this means for the UK

BBMRI-ERIC has become a well thought out infrastructure initiative that has received support from the EC and individual Member States. The potential impact of BBMRI-ERIC on biobanking in Europe, and research worldwide, is great; the initiative has gained momentum and is poised for greater activity now that the ERIC legal entity is authorised.

Many of their initiatives align with those in the UK, however the UK involvement has been at a low level to date. Although it is possible to join BBMRI-ERIC at any time in the future the timing is now pivotal if the UK wishes to have any influence on the future development of the organisation. The financial cost of membership is substantial, benefits of membership are difficult to quantify, but the dangers of being outside the organisation could be significant.

(1) http://www.ukcrc.org/infrastructure/expmed/fundersvisionforhumantissuesresources/

Involving patients/donors in biobanking: get on board

CCB Lay Members Maggie Wilcox and Derek Stewart provide their thoughts on the current situation in patient involvement in biobanking.

As previous cancer patients and people who have been involved in biobanking organisations for several years we are still surprised at the lack of genuine lay involvement in research tissue banks and large cohort studies in the UK. Patients and the public as tissue donors are key stakeholders for any organisation or project that is collecting human samples for research. Without their support and trust there would be no samples and many organisations rely on the fact that many research participants give their consent without actually being aware of what research may be undertaken or whether the sample will ever actually be used. Involving them provides reassurance that research is for genuine patient benefit and ethical considerations and high quality standards are maintained.

Biobanks and large epidemiological studies risk losing public trust by not engaging and involving them. In this article we are featuring some of the CCB member biobanks who have involved patients to show the value that this can bring and also illustrate the benefits of embedding this activity throughout the organisation of the biobank; a position that the NCRI and Confederation of Biobanks are fully supportive of and recommend in their biobanking standard.

In the early days of planning both the Wales Cancer Bank (WCB) and Breast Cancer Campaign Tissue Bank (BCCTB) patients and lay persons were involved in discussions about the scope and proposal for developing the tissue banks.

In Wales patients were part of the Steering Group that developed the bid for funding and establishment of the tissue bank. They also provided key input into the participant information sheet and consent forms as well as advising on the Ethics committee application and when to approach patients regarding tissue donation.

The input on this latter aspect was vital. “We would have had much more complicated processes and caused ourselves issues if we hadn’t involved our Lay Liaison Group”, Alison Parry-Jones, manager of Wales Cancer Bank told us. “We had pre-conceived ideas of how sensitive patients might be at the time of being diagnosed with cancer and were told very firmly by our lay colleagues that we should just go ahead and approach them. If it’s not a good time they’ll tell us but they are people they’re not made of glass.”

This challenging of pre-conceptions was also apparent during the establishment of the BCCTB who included two patients on their Management Board when the applications to host the bank were being reviewed. Alastair Thompson, Chair of BCCTB highlights, “As researchers and clinicians we saw this as a competitive process but rather than looking for a single winner, our lay colleagues challenged us to rethink the process and said – ‘there are several good bids - why can’t they work together to create a virtual bank?’ It’s fair to say the altruism of patients donating tissues to the bank is enhanced by those patient advocates guiding the workings of the bank.”

This process was a learning opportunity for both the lay members and the professionals involved. We were able to increase our understanding of cancer biology and biobanking processes and our professional colleagues their understanding of the concerns and needs of potential donors.

Indeed for brainstrust the development of the bank wouldn’t have got off the ground without patient and lay support. ‘Lay involvement is putting the collection of brain tumour tissue on the map’, commented Helen Bulbeck, Director of brainstrust.

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'Talking about tissue donation means that patients are carving out the time and space to raise this issue with clinicians so that patients are driving the agenda.' Archive brain tumour tissue is currently being recorded into one UK virtual brain tumour tissue bank, soon to be followed by post surgical collection and recording of brain tumour tissue across several neuroscience centres. This project will provide the interface that is needed between researchers, patients and brain tumour tissue, giving easy access to the right tissue, in sufficiently large numbers and of high quality. It will support a diverse range of brain tumour research projects and change the face of neuro-oncology research. And it's all down to the patient.

At BCCTB there are lay members on the Access Committee and all researchers applying for samples need to complete a lay summary of the research they plan to undertake with the samples.

In Wales lay members are part of a Lay Liaison and Ethics Group and provide input and advice on wider aspects of the tissue bank such as their communication strategy. 'We feel we're the ambassadors of the bank", said Bob Hall, the Group's Chair, "We provide a vital connection between the bank and the potential donors. We've lobbied government and encouraged the bank to go out into the community to give talks to patient groups."

The role of ambassador and advocate is one that many patients take on when they become involved in research and tissue banking is no different. Raising of awareness of research using tissue samples is becoming even more important with the development of genomic technologies and the need for samples to be collected at multiple timepoints to monitor the progression of diseases like cancer. The consent and willingness of patients and the public to participate in this research will be vital and the involvement of patients and the public will help ensure that the trust and transparency required can be maintained.

From the patients perspective this can be a very rewarding activity. It is fascinating and exciting to learn about the science being carried out with the samples and donors really want to know how they are helping progress in medical research. Many biobanks don't even send a newsletter to their donors or have information on their website about the research being carried out. How will they continue to be sustainable if they don't capitalise on the additional resource that their donors can provide in becoming advocates for them?

> "It is vital that patients have a say in how the Breast Cancer Campaign Tissue Bank works. The patient advocates involved with the Breast Cancer Campaign Tissue Bank make sure the patient perspective is considered in all key decisions." Dr Lisa Wilde, Director of Research, Breast Cancer Campaign

Standardising biobank data

Phil Quinlan, IT Lead for Breast Cancer Campaign Tissue Bank and co-chair of the NCRI's Harmonisation Project Working Group on Biobank Governance and IT, provides an update on the CCB data standard and reports back on the workshop on Data Standardisation and Integration held in Dundee in July.

Standardising a biobanking dataset

As part of the remit of the Working Group on Biobank Governance and IT we looked to establish a data standard to enable tissue banks to communicate about their holdings and facilitate development of an integrated national network of tissue banks. The standard needed to:

- use existing standards where applicable
- cater for different types of collections
- allow for multiple disease types
- not dictate data terms

There is an array of different types of biobanks in the UK that collect clinical samples. The main priority of the standard was to ensure that any biobank could communicate about the samples they hold. Therefore the minimum standard, borrowed heavily from the MIABIS[1] standard and therefore is designed to allow a biobank to broadly describe the samples it holds. However, at the same time, there is clear benefit to allow the researcher a greater search capability – such as to search on sample level information.

As there is an array of different biobanks there is an equal array of the information collected by each biobank on the samples they hold. Just because a biobank cannot provide one field, should not mean that bank cannot be part of a network. Therefore, the standard is meant to be inclusive and allows a biobank to specify information as 'Unknown'. In addition, the standard can be extended for disease specific applications. This is to ensure that the CCB standard is adopted for the core information about samples that is applicable to all diseases. The Breast Cancer Campaign Tissue Bank and the STRATUM project have developed extensions to suit their disease specific requirements.

One of the barriers to the creation or adoption of other data standards is the use of data terms that are not universally used. Therefore this standard has not specified any data terms. Tables such as 'DiagnosisCode' and 'Organ' allow the biobank to provide their own data terms. The aim is to encourage the use of standards without dictating the exact terms that should be used.

In the first real world test of the standard, the Edinburgh and Dundee ECMC centre used it to share information about the samples held within each centre's biobank. Combining the data standard with the technology behind the Breast Cancer Campaign Tissue Bank has resulted in a proof of concept system demonstrating how this standard could be applied to a national sample system for the future and delivering the long term goal of the CCB to develop a national search system to allow any researcher to find samples available across the UK.

This work is currently being drafted into a publication and will be submitted shortly. The latest draft of the standard is available (**http://www.ncri.org.uk/ccb/documents/data_standard.pdf**), but in the meantime contact Phil Quinlan (**p.quinlan@dundee.ac.uk**) if you are interested in providing further feedback or if you are interested in using the standard within your biobank or network.

High interest in data standardisation and integration in biobanking

There is clearly a need for more networking opportunities and communication about handling data in biobanking as the high level of interest and engagement in the workshop Tayside Tissue Bank hosted in partnership with NHS Glasgow & Greater Clyde (GGC) Biorepository and CCB showed.

The workshop was chaired by Professor Massimo Pignatelli of NHS GGC Biorepository and as well as myself five speakers gave presentations. These comprised Balwir Matharoo-Ball of Nottingham Health Science Biobank, Monica Jones of Cancer Research UK, Marion Flood of Glasgow Safe Haven, Rachel Mager of AstraZeneca and Emily Jefferson of University of Dundee.

Afternoon workshop group sessions discussed 3 different aspects of returning research data to a biobank and we hope to share the outcomes of these discussions more widely.

The presentations from the workshop can be viewed at **http://www.ncri.org.uk/ccb/DataWorkshop2013.html**

(1) Norlin, Loreana, et al. "A Minimum Data Set for Sharing Biobank Samples, Information, and Data: MIABIS." Biopreservation and Biobanking 10.4 (2012): 343-348

Getting to know you: Dr Ekaterini Blaveri, NCRI Head of Cancer Intelligence/NCIN Head of Research Coordination

Ekaterini joined the NCRI at the end of May 2013 in a role that is split between the NCRI and the National Cancer Intelligence Network (NCIN), now part of Public Health England. In this position, Ekaterini aims to shape the strategic objectives of both the NCRI and NCIN, in respect of the secondary use of routinely collected health data for cancer research, and facilitate research using such data.

At NCRI, she is also responsible for overseeing the biobanking activities and promoting and coordinating the primary and secondary uses of tissue samples for cancer research purposes. From January 2014, this will include her more direct involvement with the running and coordination of the CCB secretariat.

After finishing her PhD in Genetics at University College London, Ekaterini worked as a postdoctoral fellow for several years before working as a Programme Manager for the NCRI Informatics Initiative and as a Senior Research Funding Manager at Cancer Research UK.

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

There are a lot of things that I enjoy in my job ... Having the opportunity to work next to talented and inspirational people is definitely one of them … but if I had to pick just one, then this would be playing a part in the efforts to bring the results of cancer research into clinical practice that will drive improvements in care and clinical outcomes.

What's coming up for you in the next 12months?

2014 is going to be a busy year!

The impact that the new EU Data Protection regulation might have – should it go through the EU Parliament – on the biobanking community should not be underestimated. Understanding and influencing this process to ensure that the general regulation does not hinder health research is very important. The patients and the public have also a big role to play in this so we need to make sure that they are appropriately informed.

Linking biosamples to cancer registration is a project very close to my heart and I am currently working with the National Cancer Registration Service and members of the biobanking community to explore how this process would work. Cancer registries in England provide a national repository of detailed clinical data about cancer patients. In addition to information on diagnosis, which is already available to biobanks, the cancer registries can provide information on treatment and outcomes, all of which could be pivotal in correctly interpreting research study results and using samples to test new hypotheses.

What's the 'must-attend' conference you're going to in the next 12 months?

It has to be the Cancer Outcomes Conference 2014, 9-10 June, Birmingham – www.phe-events.org.uk/ncin and not just because NCIN is organising it…!

What is the most important lesson life has taught you?

What goes around, comes around…

What would your motto be?

… to boldly go where no man has gone before.

To provide feedback on this newsletter or to contribute articles please email us at ccb@ncri.org.uk