

- **The ethics of tissue donation: how far can we go?**
- **Sharing Human Tissue: New Opportunities, New Horizons**
- **New Members**
- **INVOLVE Conference 2010**
- **European Update**
- **Getting to know you: Cam-Uro Onc Biorepository**
- **Upcoming events**

www.ncri.org.uk/ccb

Note from the Editor

Caroline Magee, Communications Lead, onCore UK

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

We have meeting reports from some of the key meetings that have taken place this Autumn as well as an update from the Nuffield Council on Bioethics on the status of their public consultation on ethical issues raised by donation of human tissue. The preparations by the European Biobanking and Biomolecular Resources Research Infrastructure (BBMRI) for the next phase of their framework are also reviewed.

We are pleased to announce that four more biobanks have become CCB members and we have introductions to three of them in this issue. I hope you find the articles interesting and I welcome your feedback and suggestions for future articles.

For more information on CCB visit www.ncri.org.uk/ccb

The ethics of tissue donation: how far can we go?



Katharine Wright, Assistant Director, Nuffield Council on Bioethics gives an update on the status of their public consultation.

When the Nuffield Council on Bioethics opened a public consultation earlier this year on the ethical issues raised by donation of human tissue, we were not expecting to initiate the kind of intense debate that appeared in the regional, national and international media for several weeks after the launch.

“Cash for organs”

“Be an organ donor, get a free funeral!”

“Hey mister, wanna buy a kidney?”

These headlines assumed that what we were really interested in was whether providing stronger incentives to donate would make a difference to the current shortage of organs, gametes and tissue. Incentives are certainly part of our inquiry, but we are also considering much wider questions about how people feel about different kinds of donation, how far we can go in encouraging people to donate, and whether it is right to try to meet demand in the first place.

There are a range of factors that affect people’s willingness to donate, the purpose of the donation being one. Saving a life by donating an organ may be afforded higher priority than providing tissue for research in the minds of the public. Whether the tissue is to be used for public or commercial

research may also affect people’s attitudes to donation. And taking tissue during life, such as ‘waste’ tissue from an operation, might be seen as quite different from obtaining tissue after death.

However, it is clear that many people believe that obtaining more tissue for research purposes is an important endeavour, and the Council is considering a range of ways in which demand might ethically be met. Are some incentives unethical, or unethical in some situations? Would they even work? Some donors would regard altruism as the highest incentive, while others might be encouraged by better recognition of their contribution or appreciate some form of financial return.

NUFFIELD COUNCIL ON BIOETHICS

There is also potential to increase the ‘supply’ of tissue by looking at current rules about consent, as set out in the Human Tissue Act, which has imposed new limits on obtaining human tissue for research purposes. Are there ways in which tissue can be obtained more readily, whilst still protecting against unethical use? Does the Act generalise too much about different kinds of human tissue?

We received 170 responses to our consultation, providing us with reams of opinions, personal experiences, evidence and ideas. The Council is very grateful to all those who responded, including onCore UK, and will consider this information along with all the other evidence it is gathering during its 18-month inquiry. A report, with policy recommendations, will be published in autumn 2011.

Find out more: www.nuffieldbioethics.org/human-bodies

Sharing Human Tissue: New Opportunities, New Horizons

Sarah Dickson, head of the MRC Regulatory Support Centre provides a report of their recent one-day conference.

MRC

Medical
Research
Council

Approximately 300 delegates attended Birmingham's Motorcycle Museum for the MRC *Sharing Human Tissue: New*

Opportunities, New Horizons conference held on 15th September. Together they examined the practicalities of sharing human tissue collections within the research community in order to realise their full potential.

The conference organised by the MRC Regulatory Support Centre in collaboration with onCore UK and the Experimental Cancer Medicine Centre Network brought together an audience of investigators, tissue managers, funders, regulators and patient representatives. Delegates enthusiastically discussed the opportunities and barriers to increasing access to human tissue samples and the necessary elements for fair access: from tissue donation and meeting donor expectations; to the robust management of collections.

In the morning plenary, a diverse group of speakers discussed why people decide to donate, related strategic funding initiatives (MRC and NIHR Office for Clinical Research Infrastructure) and the facilitatory nature of the regulatory environment. Dr Declan Mulkeen from the MRC highlighted that researchers have more to gain than to lose by sharing, and a desire from funders to align policies on widening access to funded collections. Roger Wilson, a tissue donor and founder of the Sarcoma Trust, provided a personal perspective outlining the reasons behind his decision to donate and, more broadly, the issues patients consider. Professor James Ironside described how sharing between researchers can work within the UK Brain Banks Network, and the benefits of increased access to diseased and healthy control tissues to understand the spread and pathology of disease.

Two parallel sessions took place after lunch to encourage

further discussion. Session one focused on identifying opportunities and barriers to tissue sharing by promoting existing tools to facilitate access, NCRI access template and cancer sample registries; outlining the pharmaceutical industry approach; and exploring generic consent. Session two concentrated on the quality management of samples and linkage to clinical information, sharing best practice from British Association of Research Quality Assurance, UK Biobank, National Cancer Intelligence Network and the Wellcome Trust Sanger Institute.

Overall, discussions highlighted the need for patient and public engagement to highlight the benefits of tissue donation for medical research. An opt-in approach to consent was generally favoured over opt-out, and there was large support for broad generic consent for medical research, with a balance of information provided between the potential uses and the unknowns. Investment from funders was described as a key requirement, to provide the infrastructure to share tissues, from sample registries to facilities; and for the outcomes of research projects to feed into the system to enhance the knowledge base.

The day culminated with a funders perspective from Cancer Research UK, highlighting the importance of sharing to produce robust data from sufficient sample numbers, and to underpin new strategic areas such as stratified medicine.



Take home messages from the day included good support for fair access; the need for quality to underpin good science; and the promotion of well-managed generic consent to meet donor expectations. This successful event will help to steer future development of policy in this area.

The programme and the presentations are available from the conference website at www.rsconference.mrc.ac.uk

REMINDER

Add your details to the NCRI Cancer Biosample Directory



Biosample Search Portal

Find human biosamples for your research

Custodians of biosample collections - please don't forget to add your details to this on-line directory which is intended to be a signpost for researchers to find human biosamples for use in their research.

To view the directory visit <http://www.ncri-onix.org.uk/portal/#S103a>. For more information and details of how to get your collection included visit <http://www.oncoreuk.org>

CCB is pleased to welcome four new members to the confederation.

These are

- Newcastle Biomedicine Cancer Biobank
- UCL-Royal Free Biobank
- Nottingham Research Biorepository
- SUN Study Biobank

CCB Update asked them to tell us more about themselves and here is some information about three of them:

Newcastle Biomedicine Cancer Biobank



Newcastle Biomedicine is a partnership between Newcastle University and the Newcastle Hospitals NHS Foundation Trust, established to promote and support our very active programmes of translational research. The Newcastle Biomedicine Biobank (NBB) has recently been set up to

provide the infrastructure to consolidate and expand existing collections of tissues for use in these projects and to encourage the development of new collections across the North East. The Newcastle Biomedicine Cancer Biobank (NBCB) forms part of the NBB and is dedicated to the collection and storage of both solid and blood cancer specimens and derivatives. Funding has been secured to equip a tissue processing facility to prepare samples for analysis and storage, and an air-conditioned freezer room with remote alarm systems to monitor cryostorage. Samples can be stored at ambient temperature, -20°C, -80°C or in liquid nitrogen. Tissue processing capabilities include: routine histology, immunohistochemical analysis, preparation of tissue microarrays and digital image storage, along with DNA and RNA extraction. A web-based sample tracking system has been introduced which enables researchers to determine which samples are available for research collaborations and to ensure compliance with the HTA. Staff in the biobank also provide expert advice on applications for ethical approval, assist in establishing peer-review and governance oversight for generic biobanks and promote public engagement to highlight the importance of tissue donation and biobanking. Describing the importance of tissue banking in driving forward translational cancer research Professor Andy Hall, director of the NBB, told CCB "Without reference to primary samples many important observations in cancer research cannot be shown to be relevant to real patients with real diseases. The Newcastle Biomedicine Cancer Biobank has been established to assist researchers in providing this vital information". For more information visit www.ncl.ac.uk/business/facilities/research/nbb

UCL- Royal Free BioBank

As part of a strategic biobanking program University College London (UCL) and the Royal Free Hampstead (RFH) NHS Trust have established a new cryogenic biobank on the RFH campus of UCL. The Biobank opened in August 2009 following significant investments by UCL, the Royal Free Charity and the MRC. The UCL- Royal Free BioBank is one of a number of projects with a shared objective to improve collection of biospecimens and data at UCL and to make these collections available to researchers both within and outside of UCL. Whilst the majority of specimens



are likely to derive from cancer patients, the bank is not restricted to cancer research and will hold a broad range of material from patients and healthy volunteer donors.

The ethos of the UCL-RFH BioBank is one of facilitation. It is a repository but does not own the samples within; these remain under the control of the specific depositor. Individual researchers within UCL who wish to import current holdings or commence new collections are encouraged to approach the BioBank and set up their own sub-bank. The investigator works with the BioBank IT manager to design their specific sub-bank database which can be used for sample management and data analysis. These data are then made available for web-based searching to encourage internal and external collaborations. In a unique partnership, the haematology departments of most of the hospitals within the North Central London and West Essex Cancer Board are working with the BioBank to provide access to diagnostic samples. This will provide unrivalled access to tissues, blood and bone marrow at disease presentation and at each follow-up sampling. The repository will have capacity for up to 1 million cryogenically stored samples including tissue, cells, plasma, serum, DNA and RNA samples. It provides a flexible approach to banking and provides advice on compliance with regulatory requirements. The facility is currently accepting samples and will be fully operational in its purpose-built laboratories in early 2011.

For more information visit www.ucl.ac.uk/biobank/

SUN Study Biobank

The SUN Study Biobank was set up in January 2009 supported by generous funding from a locally based charity - The Prostate Project. The Biobank, located in the Oncology Department at the University of Surrey's Post Graduate Medical School works in conjunction with the Royal Surrey County and Frimley Park Hospitals, St George's Hospital in London, as well as the regional specialist referral centre, The St Luke's Cancer Centre. Research undertaken at the University of Surrey aims to advance the understanding of the causes of cancer and develop new methods of detection and treatment. The aim of the SUN Biobank is unique in providing a longitudinal set of quality assured blood and DNA samples from formally consented donors following the principles of ICH-GCP. We aim to collect 350 samples from men who have been investigated for Prostate Cancer of whom at least 300 have a diagnosis of cancer. 335 samples have been collected so far and stored, with many patients already having donated 4th follow-up sample. An equivalent number of negative control samples will also be available for research validation purposes. Samples are taken pre-treatment and then 6 monthly through treatment and beyond. A new study collecting samples from African-Caribbean men will be opening by January 2011. In addition to Prostate Cancer, we are expanding our Biobank to include Upper Gastrointestinal-tract, Breast and Ovarian Cancers.

"We are delighted with our recent approval of membership to the CCB which will help to improve interaction and sharing of valuable resources with the ultimate goal of improving patient care," said Biobank Director, Dr Agnieszka Michael, Senior Lecturer and Consultant Medical Oncologist.

For more information contact: A.Michael@surrey.ac.uk



For details of CCB membership benefits and how to apply contact ccb@ncri.org.uk

INVOLVE Conference 2010

Caroline Magee (CCB Update editor) attended this meeting on behalf of CCB to present a poster talk entitled “Establishing a forum for people interested in donating tissue for research”. She reports on the conference.

Over four hundred delegates gathered in Nottingham on 16-17 November for

INVOLVE

the two-day Involve conference which is held every 2 years. This was the highest attendance to date for this conference, established in 2004 by Involve, the national advisory group supporting greater public involvement in NHS, public health and social care research. A third of participants were service users, and a further third researchers so the majority of attendees were those putting public and patient involvement (PPI) into practice. This meeting is seen as the best showcase for PPI in research in the UK and the programme was packed with examples of how this is being delivered across the country. Over the two days delegates could attend 7 sessions out of a choice of a possible 52 which included poster talks, workshops, preferred papers and discussion sessions. The only downside was there was so much going on it was difficult to decide which session to go to. Keynote speeches were given by Dr Russell Hamilton, Director of Research and Development for the Department of Health and Simon Denegri, Chief Executive of the Association of Medical Research Charities (AMRC) and a member of Involve. Dr Hamilton stated his support for PPI and encouraged delegates to collect evidence of the impact PPI has made to their project to ensure these initiatives continue. Dave Ardron, Chair of the National Cancer Research Institute's

Consumer Liaison Group told me, “I was heartened by Russell Hamilton’s keynote presentation, and his full endorsement of the involvement of patients and carers in health research. For PPI to work, there should be support given to patient groups, including funds being allocated systematically for their facilitation and training. I look forward to other key figures in the establishment taking this stand on the public stage.”

Simon Denegri was impressed by the energy and commitment of the participants at the conference and felt that great progress had been made since the first Involve conference – with the medical research community now asking how to include PPI rather than why. He added that in the current climate this should be built on and those involved in PPI needed to continue to be ‘terrier-like’ in their persistence to be included in the research process.

Maggie Wilcox, member of patient advocacy group Independent Cancer Patient Voices provided her thoughts, “We need to aim for greater inclusivity of patients and the public and make sure we find appropriate ways of ensuring we don’t exclude anyone who wishes to get involved in research and that they feel their contribution is valued.”

Overall it felt at the conference that PPI is on the crest of a wave at the moment and there needs to be some concerted effort made to collect all the evidence of impact and ensure all those who are delivering it can be connected to share best practice and continue the growth of this important part of the research process.

For more information on the conference and the work of Involve visit www.invo.org.uk.

European Update



The preparations by the European Biobanking and Biomolecular Resources Research Infrastructure (BBMRI) for the next phase of their framework are reviewed by Derick Mitchell, Executive Manager for the BBMRI Stakeholder's Forum.

It has been a busy last five months for BBMRI, the European Biobanking and Biomolecular Resources Research

Infrastructure, which is nearing the end of the preparatory stage in the process of establishing a pan-European Biobanking Research Infrastructure. Three recent events were organised by BBMRI to highlight current challenges and the potentially enormous impacts of an implemented infrastructure.

The first, on 9th June in Brussels, was a meeting of the BBMRI Stakeholders Forum, where researchers from academia and industry, patient organisations, research administrators, biobankers, ethicists and lawyers from all across Europe came together to discuss the major issues among the broad stakeholder community of BBMRI. Highlights of the meeting included discussions on an international structure to accommodate the differences in ethical and legal landscapes among European states, integration of clinical trials and biobanks and the presentation of a Patient Consultation Document to the Steering Committee of BBMRI, highlighting participation for patient representatives in the implemented research infrastructure.

The second conference entitled “BBMRI: Biobanking for Science”, was held in Amsterdam between September 23rd-

25th, where the science and new approaches in cutting edge biobank research were presented and discussed. In a truly world-class lineup, keynote speakers presented on, for example, “Integrating Electronic Patient Records and Biobanking”, “Translating Cancer Genomes into Personalized Health and Disease Management” and “Private-Public Collaboration and Biobanking Science”. New developments in data mining, data analysis and data protection as well as emerging and enabling technologies in biobanking-related fields were presented and debated among the 250 participants representing over 22 European countries.

The third event was a public hearing held in the European Parliament, Brussels on October 26th entitled “Health related Research Infrastructures and their contribution to their EU’s grand challenges”. This event was held to determine how the EU’s biological and medical science research infrastructures, such as BBMRI (www.bbmri.eu), ECRIN (www.ecrin.org) and ERINHA (www.erinha.org) will contribute to key health-related strategic policy priorities. The hearing was sponsored by Dr. Paul Rübig MEP and was moderated by Clive Cookson, Science Editor of the Financial Times.



BBMRI is currently submitting an application for the new European Research Infrastructure Consortium (ERIC) legal status and aims to be operational by the beginning of 2012. Meeting reports, as well as presentations delivered are all available on www.bbmri.eu/index.php/newsevents/previous-events



Getting to know you: CamUro-Onc Biorepository

Anne George is a Research Associate in the Department of Uro-Oncology at Addenbrooke's Hospital in Cambridge. The CamUro-Onc Biorepository was set up by the department to store samples collected as part of two research programmes in prostate cancer, the **ProtecT** and **ProMPT** Studies. The collection includes blood, urine and tissue collected from over 125,000 men. The processed blood is stored as DNA, serum and plasma. Clinical and biospecimen data are recorded for each sample in the biorepository.

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

The most satisfying role of our job is meeting patients because at the end of the day if we do have willing donors there would a biobank and research would to a standstill.

What's been the toughest challenge your organisation has had to overcome?

The toughest challenge is the maze of guidelines regarding tissue storage and use which keep changing and for us to keep of top of it.

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

To streamline our collection to more specialised groups for use in urological research.

What are you doing to engage with patients/donors and the public?

As part of the urological team we meet patients in clinics on a regular basis and keep them updated on progress we have made in research.



Anne (far right) and her colleagues from the Biorepository.

What single thing would improve the quality of your biobank service?

To improve our tissue collection and processing techniques.

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

The CCB Workshop "Quality Matters" held two years ago in London, where other pathologists and tissue bankers spoke about their protocols which they use for tissue storage.

What's the best feedback you've had from a researcher who's used your biosamples?

The recent news in the BBC about a new urine test for prostate cancer can be our best feedback.

What is the most important lesson life has taught you?

To be patient. A virtue I am devoid of but am fast acquiring!

You wouldn't know it but I am really good at...

Baking, I just love it.

Upcoming Event

Britain Against Cancer 2010 'A new cancer strategy, a new NHS - making it work.'

14 December 2010, Church House, Westminster, London



The All Party Parliamentary Group on Cancer (APPGC) was founded in 1998 to keep cancer at the top of the political agenda, and to ensure that policy-making remains patient centred. The Group brings together MPs and Peers from across the political spectrum to debate key issues and campaign together to improve cancer services. The APPGC's landmark event is the **annual Britain Against Cancer conference** (<http://www.macmillan.org.uk/GetInvolved/APPG/APPG.aspx>) which provides a unique opportunity to bring together everyone who has an interest in improving cancer services in the UK.

The 7th NCRI Cancer Conference

The 7th NCRI Cancer Conference will be held at the BT Convention Centre in Liverpool on 6-9 November 2011. The Conference is the major forum in the UK for showcasing the **best British and international cancer research**, bringing together the **leading experts across all disciplines** with a compelling mix of **high-quality plenary speakers, symposia and parallel sessions**, including **focused satellite meetings and workshops**. Abstract submission opens 21st March 2011 and registration will open 1st June 2011. Please see <http://www.ncri.org.uk/ncriconference/> for a preliminary programme and additional information.



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