

2001

A decade of progress through partnership in cancer research

2011

National Cancer Research Institute NEWSLETTER



2011 Issue 3

New NCRI Board Member representing smaller charities

Inside this issue:

Ensuring wider access to tissue samples for research

Spotlight on recipients of End of Life Care research awards

Biomedical informatics without borders: Building on collaborations

Expanding the use of PET in clinical cancer research

NCRN Roadshow celebrates 10 year anniversary and looks forward



We are delighted that Mr Eric Low, Chief Executive of Myeloma UK, has joined the NCRI Board as an independent member.

Eric set up Myeloma UK in 1997. The charity currently employs 25 members of staff, providing a broad range of services covering every aspect of myeloma from information and support, to improving standards of treatment and care through research, education, campaigning and raising awareness. As Chief Executive, Eric has been instrumental in developing the organisation's

'bench-to-bedside' strategy, an integrated model to systematically address patients' needs.

Eric commented, "I'm thrilled to have been appointed to the Board. The NCRI has achieved a great deal over the last decade and I hope I can make a significant contribution to its future success." He continued, "Although this position involves strategic thinking around all cancers, I will be aiming to make sure that rare cancers are strongly represented."

Professor Dame Janet Husband, NCRI Chair said, "We look forward to working with Eric and benefitting from the wealth of experience he brings to the table."

Connecting consumers in NCRI

NCRI includes consumers (defined as patients, carers and others affected by cancer) in all NCRI management groups, committees and initiatives. A new Consumer Networking Group (CNG) for these consumer members is being established to facilitate sharing of experiences and encourage greater interactions between the members. One of their aims is to improve their understanding of the bigger picture of current NCRI activities so that they in turn can use their combined experience and connections to help provide additional momentum to these activities.

An initial scoping meeting was held in early October attended by the consumer members and representatives of the NCRI Secretariat and NCRI Consumer Liaison Group (CLG). Mrs Lesley Roberts (pictured), consumer member of one of the CTRad workstreams, has agreed to act as interim chair of the group.

The group's initial activities will focus on defining their Terms of Reference and they are already planning to hold a workshop in the coming months on how consumers

can inform and influence at a strategic level. The group will work closely with the NCRI CLG (which is largely made up of consumer



members of the Clinical Studies Groups) and will take forward topics that have been proposed by the CLG as well as initiating their own activities. For more information contact angela.hagan@ncri.org.uk.

NCRI strategy for next 5 years

NCRI is developing a strategy for the next five years, that will come on stream in 2012. Consultation documents will be posted on the NCRI website www.ncri.org.uk during November.

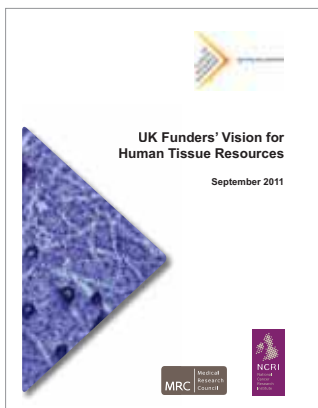
www.ncri.org.uk

Several complementary initiatives have come together to give this important activity some increased momentum.

Funders vision for Human Tissue Resources

UK funders of experimental medicine have agreed a common vision for their investment in human tissue resources. In summary, this is:

"...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."



This vision has been endorsed by the Experimental Medicine Funders Group of the UK Clinical Research Collaboration (UKCRC) and by the Board of the NCRI; a growing number of individual funders have committed to the vision and the principles that support it. The NCRI's Consumer Liaison Group contributed to the report

and lay summary, and positive discussions also took place with the Nuffield Council on Bioethics, whose own report on "Human bodies: donation for medicine and research", published in October, endorsed several of the UKCRC report's recommendations.

The full project report, lay summary and recommendations for implementation are available for download at <http://bit.ly/UKCRCFundersVision>. These are presented for wider comment and will be reviewed in early 2012. Please send any comments to info@rsc.mrc.sc.uk by 2 January 2012.

Working towards the vision

Working to similar ends, the Technology Strategy Board is funding a public-private partnership, STRATUM - Strategic Tissue Repository Alliance Through Unified Methodology - to increase the effectiveness of tissue sample collection and storage. Over a period of 18

months, from November 2011, STRATUM will create the foundations of a UK biobanking network. Bearing in mind the commonality of purpose, a series of joint groups will work to deliver both the STRATUM and UKCRC objectives. These will be overseen by the STRATUM steering group with representation from funders, industry and academic researchers. By this means it is hoped to achieve convergence of activities that began in different disease areas. STRATUM workstreams will cover topics including consent, public engagement, technical standards, sample characterisation datasets and cost models.

Harmonisation and bench-marking of cancer biobanks

The NCRI's Confederation of Cancer Biobanks has launched a project to develop a benchmarking or accreditation scheme for research tissue banks. A kick-off meeting was held on 23 September at the Wellcome Collection Conference Centre in London. The day began with presentations describing the importance of the project to stakeholders including funders, patients and researchers, and gave an international perspective on how issues are being addressed elsewhere. The afternoon consisted of two consecutive workshops, entitled 'Harmonisation and standardisation', and 'Benchmarking, certification and accreditation'. Delegates discussed the options for the scheme and the incentives and barriers to participation. The proposal received broad support at the meeting. Increasing the availability of high quality, well annotated samples was seen as the most important benefit of the project; however participants also emphasised that a costly, overly bureaucratic, scheme must be avoided. A draft action plan is being drawn up and will be taken forward by a small Steering Group supported by several Working Groups. There has been strong interest in membership of these groups and it is anticipated that the Steering Group will hold its first meeting in late 2011 or early 2012.

For more information contact ccb@ncri.org.uk



Biomedical informatics without borders: Building on collaborations

The fifth Joint Conference of the U.S. National Cancer Institute cancer Biomedical Informatics Grid® (caBIG®) and the NCRI Informatics Initiative took place in London during the summer.

This series of events has presented a unique opportunity to formulate creative collaborations, bringing together as they do, a wealth of expertise and knowledge from around the world. This year the themes were:

- Sharing Data from Large-Scale Genomic Studies
- Imaging

- Use of Clinical Data for Research Purposes
- Standards and Vocabularies
- Tools and Technologies

Small groups worked on each theme, to address key, unresolved issues. Each group produced recommendations, commitments and collaborative proposals which will be taken forward in the coming months. These experiences will form the basis for a number of peer reviewed papers.

Further information on the meeting and copies of presentations can be seen at

www.cancerinformatics.org.uk/jointconference_11.html

Spotlight on recipients of End of Life Care research awards



Marie Curie Cancer Care has announced the first awards from its two

open and competitive palliative and end of life care research programmes.

The Marie Curie Cancer Care Research Programme, administered by Cancer Research UK, has awarded more than £1 million to six projects aiming to improve end of life care for people with cancer or other life-limiting conditions. The call attracted a high number of applications and an independent funding committee, chaired by Professor Sir Andy Haines, awarded six grants to the following projects:

- **Dr Maureen Coombs** and **Professor Alison Richardson** (Southampton University Hospitals and University of Southampton). 'An investigation about transferring patients in critical care home to die: experiences, attitudes, population characteristics and practice.'
- **Mr Andrew Dickman** (University of Liverpool). 'Chemical compatibility of drugs administered by continuous subcutaneous infusion for end of life care.'
- **Dr Catherine Evans** (King's College London). 'Mental capacity and processes of informed consent for research on end of life care.'
- **Dr Debra Howell** (University of York). 'Exploration of factors associated with place of care and place of death in patients with haematological malignancies.'
- **Professor Sheila Payne** (Lancaster University). 'Unpacking the home: family carers' reflections on dying at home.'

- **Professor Jane Seymour** (University of Nottingham). 'Understanding the role of nurses in decisions to use anticipatory prescriptions to manage symptoms and distress in the last days of life: a prospective community based case study using mixed methods.'

The Dimbleby Marie Curie Cancer Care Research Fund, in partnership with



Dimbleby Cancer Care, has awarded £440,000 to three projects. The projects focus on research into the role of volunteers in improving end of life care for patients and their families. Proposals were peer reviewed and an independent funding committee, chaired by Dr Bill Noble, awarded three grants to the following projects:

- **Mr Nick Ockenden** (Institute for Volunteering Research). 'Meeting the specific challenges of involving volunteers in palliative care roles which require direct contact with patients or their families.'
- **Ms Bridget Candy** (University College London). 'How volunteers may improve end of life care: an evidence synthesis and qualitative and quantitative research and survey of current practice.'
- **Professor John Ellershaw** (University of Liverpool). 'A living community presence: an innovative approach for volunteers to support the care of patients and their families in the last hours and days of life.'

To find out more, view the videos of some of the grant recipients at

www.mariecurie.org.uk/2011researchawards or visit the Marie Curie research website for more information www.mariecurie.org.uk/en-gb/research/

Expanding the use of PET in clinical cancer research



Practical advice on designing imaging

studies in oncology using PET (Positron Emission Tomography) and information on imaging with particular tracers was provided to researchers at a recent one-day workshop hosted jointly by the Biomarkers and Imaging Clinical Studies Group (CSG) and the NCRI PET Research Initiative. Around 100 delegates attended from across the 21 other CSGs.

The workshop was chaired by Prof Fiona Gilbert (University of Aberdeen, pictured) who is a member of both the organising groups. Resources for researchers wishing to use PET in studies include the NCRI PET Core Lab which provides a co-ordination function for UK-based PET trials. The group is based at St Thomas' and accredits sites to

the NCRI PET Clinical Trials Network, harmonises standards, and performs QA (quality assurance) for multicentre trials. For more details contact pet-trials@kcl.ac.uk.

Further resources to support PET researchers are available at www.ncri-pet.org.uk. These include the PET scan funding flowcharts discussed in the workshop, details of which centres are accredited as part of the NCRI PET Trials Network and databases indicating availability of novel radiotracers and facilities at different sites around the UK.





The National Institute for Health Research Cancer Research Network (NCRN) recently hosted a series of regional meetings aimed at the NHS workforce supporting delivery of cancer studies in the NIHR Clinical Research Network portfolio. 360

delegates from across the networks attended from the full spectrum of roles including Managers, Research Nurses and Clinical Trial Practitioners, Data Managers and Administrators together with Consumers and colleagues from stakeholder organisations including funding bodies and the pharmaceutical industry.

The aim was for the NCRN Coordinating Centre leadership to reach out directly to staff on the ground to mark the 10th Anniversary of NCRN, to celebrate NCRN's achievements with those who have been instrumental to its success, and to engage and motivate network staff to meet the challenges ahead. It also provided

the opportunity to launch the modified branding for the organisation (shown here).

The programme included addresses from the NCRN Director and Assistant Directors highlighting NCRN's achievements, reaching cancer study recruitment levels of over 46,000 patients in 2010/11 (equivalent to 19.8% of new incident cancers). Other sessions included results of key trials and a joint NCRN/Pharmaceutical Industry session celebrating the progress in the NCRN adopted commercial portfolio. Other sessions enabled Local Research Network staff to share experience and good practice and for Clinical Study Groups (CSG) Portfolio Maps to be highlighted. Professors David Cameron, Peter Johnson and Tim Maughan provided their personal perspective on the impact of NCRN in its first decade.



“Thanks for the opportunity to attend this conference. I found it enjoyable and highly informative. It also gave me a real sense of pride at being a part of something so successful and yet still with so much potential”



Save the date....



2012 NCRI Cancer Conference

BT Convention Centre, Liverpool, UK

4-7 November 2012

Please check the Conference website for further information and updates on additional plenary speakers, parallel sessions and workshops

www.ncri.org.uk/ncriconference

PLENARY SPEAKERS

- Kenneth Anderson (USA)
- Robert Bristow (Canada)
- Eduardo Bruera (USA)
- Judy Garber (USA)
- William Hahn (USA)
- Lee Helman (USA)
- Harpal Kumar (UK)
- Joan Massagué (USA)
- Neal Rosen (USA)

ALSO FEATURING SYMPOSIA ON

- Imaging and cancer therapy
Hosted by TBC
- Cancer evolution
Hosted by Gerard Evan (UK)
- Cancer in the developing world
Hosted by TBC
- The challenges of drug development
Hosted by Susan Galbraith (UK)
- Cancer susceptibility
Hosted by Bruce Ponder (UK)
- Palliative and supportive care
Hosted by Irene Higginson (UK)
- Tumour immunology
Hosted by Adrian Hayday (UK)
- The tumour microenvironment
Hosted by Margaret Frame (UK)