



JANUARY 2009

New Year Greetings from NCRI

2008 proved to be another busy year for NCRI and we would like to take the opportunity to thank everyone who contributed in some way to our publications or initiatives.

Three new publications came out during the last 9 months of the year - the Strategic Plan for 2008-2013, an analysis of 5 years' data from the Cancer Research Database, and a Rapid Review of Radiotherapy and Related Radiobiology. The last of these is reported on further below and all three can be found on the NCRI website at <http://www.ncri.org.uk/default.asp?s=2&p=4>, with hard copies available on request.

The fourth NCRI Cancer Conference in Birmingham in October went with a real swing, and with some delegates telling us it was the best yet. See the back page of the newsletter for details of this year's event. Abstracts and

podcasts from previous years continue to be available on the Conference website at <http://www.ncri.org.uk/ncriconference/>

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Turning to other forthcoming activities, a number of new initiatives are being kicked off, others will come to fruition and yet others will be reviewed so that decisions can be made about their future. We will continue to provide brief updates on them all in our newsletters. In these challenging times, we cannot afford to rest on our laurels, and we welcome constructive feedback from colleagues and friends, whether professionals or consumers, at any time, by e-mail to info@ncri.org.uk.

Diversifying NCRI's links

The membership of NCRI currently stands at 20 government and charity funders of cancer research plus the Association of British Pharmaceutical Industry (ABPI).

To be a full member requires a spend of over £1m pa on cancer research in the UK, and distribution of funds by independent peer review. However, our activities are open to any other organisation that wishes to make a contribution, whether in cash or in kind, and we are always

willing to share information and experience of partnership working. During 2008, NCRI was involved in active discussions with the following charities and consortia: UK Respiratory Research Collaborative, Cancer 52 Group, Samantha Dixon Brain Tumour Trust, The Prostate Cancer Charity, and the Prostate Cancer Charter for Action. In early 2009, further meetings will take place with the Cancer 52 Group, the Teenage Cancer Trust and the Ovarian Cancer Early Diagnosis Research Interest Group. Engaging

with a wider group of organisations in this way helps NCRI to broaden its view of cancer research, and its ability to make new connections.

Being part of NCRI does not have to be expensive. You can sponsor a session at the NCRI Conference and raise your profile in the research community for as little as £10k +VAT. If you are a charity interested in cancer research and would like to get involved with NCRI please contact us via info@ncri.org.uk or conference@ncri.org.uk

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A new opportunity for radiotherapy research in the UK

Radiotherapy contributes to the treatment of many patients diagnosed with cancer and is second only to surgery in its curative effectiveness.

Major technological developments are now improving the targeting of radiotherapy treatment to tumours in the body, with the expectation of reducing both short and long term side effects arising from damage to healthy tissue. When used in combination with some of the new drug treatments being developed, radiotherapy has the potential to be even more effective.

The opportunity for research is therefore considerable and, following a rapid review of the field, the NCRI Board has agreed to establish a Clinical and Translational Radiotherapy Research Working Group with a broad, strategic remit to develop an ambitious portfolio of practice-changing trials. It will also be responsible for ensuring coordination across all aspects of radiotherapy and radiobiology research which are relevant to cancer, and for actively promoting translation of new discoveries into practice. Professor Tim Maughan of Cardiff University has agreed to be the interim chair of the working group during its set-up phase. The new Working Group subsumes the role of the former Radiotherapy Clinical Studies Group.

The Working Group will establish four workstreams to take forward the programme of work entrusted to it by the NCRI Board, each led by two co-chairs and with multidisciplinary membership. Applications to join workstreams as either a member or co-chair are currently being invited in open competition.

The report of the rapid review and further information on the workstreams and appointment process can be found on the NCRI website at <http://www.ncri.org.uk/default.asp?s=1&p=5&ss=14>

Launch of the National Awareness and Early Diagnosis initiative (NAEDI)



The aim of NAEDI is to improve clinical outcomes for patients by diagnosing cancer earlier than at present.

At the launch meeting in London on 21 November 2008, Professor Mike Richards (shown above), National Cancer Director for England, spoke eloquently about 'The Size of the Prize'. He told delegates that if the UK had been able to match the best cancer survival rates in Europe, we could have saved about 11,000 lives every year between 1995 and 1999, and 8-10,000 per year between

2005 and 2009. He suggested that over half these deaths could be avoided simply by raising awareness among the public of cancer symptoms and encouraging them to seek treatment early. Hundreds of delegates attended from Primary Care Trusts, General Practices, Cancer Networks and charities, and many have gone away determined to develop local projects to promote awareness. At national level, a Cancer Awareness Measure (CAM) has been developed and surveys of the public's knowledge of cancer symptoms have begun to provide a baseline against which the effectiveness of new interventions can be assessed. Wider research programmes will also be planned with Cancer Research UK as the lead partner within NCRI.

Further information about NAEDI and the launch can be found at www.naedi.org.uk.

Lung Cancer Screening Study



Lung cancer is one of the tumours that is often diagnosed at a stage when it is too late for it to be cured by surgery.

While raising awareness of symptoms provides one approach to early diagnosis, another is to screen people at high risk of contracting lung cancer – if an effective screening test can be found. NCRI's report on lung cancer research in 2006 led to an outline economic assessment as to whether screening with spiral computed tomography (spiral CT) was likely to be affordable by the NHS. An encouraging result from this study has now led to a

feasibility study for a clinical trial, led by Professor John Field, Director of the Roy Castle Lung Cancer Foundation Research Programme at the University of Liverpool, and funded by the National Institute of Health Research's (NIHR's) Health Technology Assessment (HTA) Programme, thus forming an alliance between two of NCRI's partners. If successful this study could be followed by a pilot study and potentially a larger randomised controlled trial to determine whether the test is good enough to help reduce mortality from lung cancer. Further economic assessment would also be necessary as part of a full trial. The best defence against lung cancer is still not to smoke or to give up if you already smoke. However for those who are already at risk, an effective screening test could be a life-saver.

Further information about the feasibility study can be found at <http://www.hta.ac.uk/1752>.



Workshop on ethics and governance in cancer biobanking

On 7 January, the NCRI Confederation of Cancer Biobanks (CCB), in association with the Pathological Society, held a well-attended workshop on ethics and governance in cancer biobanking.

The meeting, sponsored by onCore UK (www.oncoreuk.org) and the Experimental Cancer Medicine Centres (ECMC) Secretariat (www.ecmcnetwork.org.uk), attracted over 170 delegates including representatives of biobanking organisations, consumer groups, funding organisations and regulatory bodies.

The workshop featured talks by Brian Clark (onCore UK; shown right) on the guiding principles which underpin the CCB, Alison Parry Jones (Wales Cancer Bank) on the essential elements of generic and enduring consent and David Neal (National Research Ethics Service, NRES) on the ethical review of research tissue banks.

Harry Cayton, Chair of the recently established National Information Governance Board (NIGB), highlighted the central objectives of NIGB namely to create a way for safe and secure ethical data sharing to take place by providing leadership and promoting consistent standards for information governance across health and social care. For more information on the NIBG, go to www.connectingforhealth.nhs.uk/nigb.

Adrian McNeil, Chief Executive of the Human Tissue Authority (HTA), took to the podium for a Question and Answer session on the Human

Tissue Act and the HTA licensing process. It was highlighted that the HTA is currently running a consultation on a proposed new licences fee structure, which can be found at www.hta.gov.uk/consultations_and_events/current_consultations.cfm.

Martin Yuille of the UK DNA Banking Network (UDBN) explained the processes in place at UDBN to enable sample collectors to work together and provide fair access to the samples which respects the differing interests of the patients, principal investigators, external researchers, employers and the research funding organisations. In the final session of the workshop Graeme Laurie described the governance model employed by UK Biobank. Derek Stewart (Chair, CCB) rounded off the workshop emphasising the importance of comprehensive stakeholder engagement in order to gain widespread awareness and support for biobanking in the community.



Further information about the Confederation of Cancer Biobanks can be found at www.ncri.org.uk/ccb, where presentations from the workshop will be available shortly

Access to personal data and biosamples

The recent workshop illustrated the current high level of interest in the governance of access to personal data and biosamples.

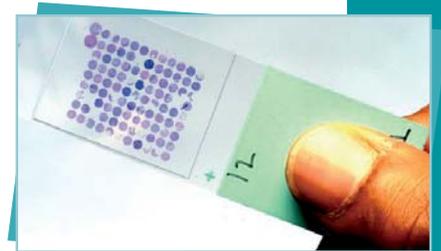
Investigators, regulators and research funders, as well as patients who provide data and tissues all have an interest in ensuring that these resources are used ethically and effectively in research for the public good. Partly because of the number and variety of stakeholder interests, there has been a proliferation of advice and guidance which can be daunting for anyone starting a data or tissue collection and needing to develop an access policy. NCRI is looking to consolidate current good practice into two template documents, both of which are intended to be practical instruments for writing a new policy: (i) a list of terms for an access policy for a specific collection of data or samples, with options for tailoring to circumstance, and (ii) a template Data and Material Transfer Agreement (MTA). The aim is to avoid the continual re-duplication of effort involved in mastering the current body of guidance. Reference to key guidance documents will be included and updated as needed.

The NCRI's consultation on this subject (run in collaboration with onCore UK and the National Cancer Intelligence Network (NCIN)) has now closed and the results are being collated. The number of responses and the level of support received give us confidence that

the proposed resources will be of value to the cancer research community and beyond. While it is not possible to anticipate every circumstance that might need to influence an individual policy, the consultation showed reasonable agreement on a broad range of issues.

During the first quarter of 2009, we will publish a summary of the range of opinions expressed, highlighting areas of general consensus, and of difference. We will also release initial versions of the template documents. Our aim is that they will be serviceable at that point and that they will also be subject to further discussion and refinement over time. We will greatly value feedback from users so that we can improve the documents in the light of experience.

If you have any comments at this stage or would like further information on the consultation and its outcomes, please email us at access@ncri.org.uk. Further information and the consultation document can also be accessed at <http://www.ncri.org.uk/default.asp?s=1&p=8&ss=9>. While the formal consultation has closed, further comment will be welcomed.



Consumer feedback from the 2008 NCRI Cancer Conference

From **David Ardron**, Chair, NCRI Consumer Liaison Group

“The Annual Conference of the NCRI welcomes delegates from many disciplines, and not least amongst those gathered in Birmingham in October 2008 were the 45 consumer bursary holders, patients and carers from across Britain, who attend and enrich almost every one of the sessions presented.

The comments of three of the patients at the conference underline the value of these bursaries.

“My overall view of the conference was that it was organised superbly well, and met all my expectations and more” **Malcolm Cole**

“I formed a much stronger impression of the cancer research industry. It was useful to see the people and the organisations involved and to get a sense of the types of discussions that people are having. I was very impressed by the way that consumers were welcomed into the conference and their views sought and considered.” **Julie Clifton**

“The Conference was packed with presentations of very high quality and remains a valuable and important vehicle for consumers to get to grips with the complexity of cancer.” **Jill Bartrop**

The Consumer Liaison Group will seek to foster these relationships at future conferences. Many thanks to NCRI for their generosity, not just financial, but also intellectual. The wealth of experience gained by these bursary holders can only serve to enrich and enhance the contribution of consumers to the research process. ”

Applications for consumer bursaries for the 2009 NCRI Conference will be available in the Spring. For further information, contact Angela Hagan. angela.hagan@ncri.org.uk



www.ncri.org.uk

Sunday 4 October – Wednesday 7 October 2009

The International Convention Centre, Birmingham, UK

www.ncri.org.uk/ncriconference



2009 NCRI Cancer Conference

Abstract submission opens 2 March

Plenary speakers:

Alan Ashworth (UK)

Gerard Evan (USA)

Ian Tannock (Canada)

Illora Finlay (UK)

Larry Norton (USA)

Marc Buyse (Belgium)

Maria Blasco (Spain)

Mel Greaves (UK)

Paul Workman (UK)

Suzanne Cory (Australia)

William Kaelin (USA)

Supportive and Palliative Care (SuPaC) Collaboratives

The two SuPaC Collaboratives started formally in April 2006 to develop research capacity in the area, increase the extent of interdisciplinary group working and to promote collaboration and sharing of research expertise.

Each Collaborative is a consortium of groups from a number of universities and each has taken a number of broad research themes around which to build their research capacity. The **Cancer Experiences Collaborative (CECo)** has three inter-related research themes: innovative approaches to complex symptoms; planning for the care of older adults towards the end of life; and narratives of cancer and other life limiting illnesses. The second Collaborative is known as **COMPASS (COMPLex interventions, Assessment, trialS and implementation of Services)** and focuses on methods for patient assessment, developing and evaluating new interventions, and the evaluation of approaches to training health professionals to deliver supportive and palliative care.

A mid-term review of progress showed that the Collaboratives are succeeding in their aims through a variety of activities, including workshops, master classes, protocol development meetings, pre- and post-doctoral fellowships, mentoring and annual scientific meetings. Success is starting to show up in increased grant income, collaborative publications and staff moving on to more senior appointments in the field. Having passed the mid-point of their tenure, the Collaboratives and NCRI are starting to think about how to sustain the momentum that has been created and continue the capacity-building process. New Government strategies in England in the areas of survivorship and End-of-Life Care are likely to lead to the availability of funds for research in these areas, and thought is now being given to how these different activities can be dovetailed, and taken forward symbiotically.

For more information about the NCRI SuPaC Collaboratives or to get involved, go to www.ceco.org.uk and www.compasscollaborative.com.

If you have any comments or news stories for inclusion in future editions of the NCRI newsletter, please contact:

info@ncri.org.uk