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5-year analysis from the NCRI Cancer Research Database

When the NCRI Partners came together in 2001, one of their first acts was to share information on the cancer research they were funding, enabling a national portfolio to be developed and analysed for the first time.

The results were published in the 2002 Strategic Analysis (http://www.ncri.org.uk/includes/Publications/reports/ncri_strategic_analysis_2002.pdf). NCRI has continued to collect information each year and has now published a summary from the first five years of data, allowing trends and changes over time to be revealed. In the years 2002 to 2006 inclusive, NCRI

partners spent £1.6bn on cancer research in the UK, with the annual spend rising from £257m in 2002 to £393m in 2006. Part of the rise is due to new partners and the effect of inflation, though in part it does appear to be a real increase. Other trends are less marked though there has been an increase in prevention research from £6m in 2002 to £14m in 2006, ie from 2.3% of the portfolio to 3.6%.

Go to <http://www.ncri.org.uk/includes/Publications/reports/analysisReport08.pdf> to see the full published analysis.



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National Cancer Survivorship Initiative

On 11 September 2008, the Department of Health and Macmillan Cancer Support launched the National Cancer Survivorship Initiative (NCSI) at a meeting in London.

A cancer survivor is someone who has had a diagnosis of cancer at some point in their life; they may have active disease or they may be living beyond their cancer. Recent research has highlighted that by the end of 2008 there will be 2 million cancer survivors in the UK, and that this figure is expected to rise at over 3% a year.

A Think Tank event, attended by a wide variety of stakeholders including researchers, consumers

and research funding organisations, held earlier this year highlighted that survivors of cancer have a range of physical, psychological, social, spiritual, financial and information needs. Seven NCSI workstreams have since been set up to look into the health care services and support available and how these may be improved, extended and adapted to best serve the needs of survivors. The seven workstreams are;

- Assessment, care planning and immediate post treatment approaches to care
- Managing active and advanced disease
- Late effects
- Children and young people
- Self care and self management

- Work and finance
- Research

The NCSI research workstream is being chaired by John Neate, Chief Executive of The Prostate Cancer Charity and NCRI Board Member. This will bring together NCRI Partners, representatives of other cancer charities, researchers and consumers in order to identify the knowledge gaps and define the future research agenda in the area of survivorship.

Further information on the NCSI and the work of the individual workstreams can be found at <http://www.improvement.nhs.uk/cancer/survivorship.html>.

Annual Meeting of the International Cancer Research Partnership (ICRP)



This Partnership was formed in 2000, when ten cancer research funders from the US and the UK agreed to use a common system to categorise their research portfolios (known as the Common Scientific Outline), enabling comparison among different organisations and countries

The Partnership has since grown and now includes all NCRI partners as well as the Canadian Cancer Research Alliance of more than 20 partners. The database of over 40,000 research projects is available through the ICRP website (www.cancerportfolio.org), and a summary analysis is in preparation for publication.

The Partners meet mostly by teleconference and each year one partner hosts a face-to-face meeting - this year it was the turn of NCRI to host the annual meeting in London. This provided the opportunity for our own partners to join in, and as well as welcoming our colleagues from the US and Canada, we invited representatives from cancer research funders in other European countries, to share information with them and invite them to consider joining the partnership. This proved to be an excellent networking opportunity for all concerned and a number of new alliances and joint activities are under discussion as a result.



International Cancer Research Partners

National Awareness & Early Diagnosis Initiative

Like the survivorship initiative, the National Awareness and Early Diagnosis Initiative (NAEDI) was announced in the Cancer Reform Strategy for England, published in December 2007, and will be taken forward in partnership with a number of organisations, including NCRI

In this case, also, research is one of 7 workstreams being pursued in the first instance:

- Review of evidence base
- Measuring symptom awareness and undertaking surveys
- Interventions to promote early presentation
- Understanding the nature of primary care delay
- International benchmarking of outcomes
- Research to fill gaps in the knowledge base

- Key messages for individual cancers

The research workstream will be chaired by Harpal Kumar, Chief Executive of Cancer Research UK, and will explore a wide range of topics from improving our understanding of what drives symptom awareness & health behaviours, to the development of GP decision-making tools and study of biomarkers for diagnosis and screening. It will take on board literature reviews and information about current research and other awareness-raising activities of NCRI partners in developing a research agenda for the next few years.

A launch event will be held on 21 November in London. Further information about this and about NAEDI generally will appear at this web address: <http://info.cancerresearchuk.org/public-policy/naedi/?a=5441>

Access to personal data and biosamples

The issues relating to access to personal data and biosamples for research are being much debated in many arenas. In the cancer research community we are looking to provide a focus for synthesising the key points, in a way that will help to avoid individual researchers and funders repeating the same background work each time an access policy is needed for a new study or collection of data and/or samples

NCRI, in collaboration with the National Cancer Intelligence Network and onCore UK, has solicited views on the elements of policies and agreements for access to samples and data for cancer research. The ultimate aim of this work is to provide a resource in two parts: (1) A template list of terms for an access policy for a specific Collection of data or samples, with options for tailoring to circumstance:

this will be a practical instrument for writing new access policies, and (2) A template Data and Material Transfer Agreement (MTA) which can again be used by anyone as a starting point.

We have already received responses to our consultation from, amongst others, consumers, clinical researchers, biobankers and representatives of the cancer registries, and would like to hear from more people.

We have extended the consultation until 17 October 2008

If you are interested you can find the consultation document at www.ncri.org.uk and send your views to access@ncri.org.uk



New Chair for the Consumer Liaison Group



Mr David Ardron has been appointed Chair of the NCRI Consumer Liaison Group (CLG)

David's experience as a carer for both of his parents (lung and breast cancer patients) led him to want to help with research into cancer care and treatment. David has been involved in the CLG and the NCRI Lung Cancer Clinical Studies Group since 2004 and has a wide range of experience at both local and national level. David

was previously a member of the NCRI Strategic Planning Group on positron emission tomography (PET), which looked into the research needs for using PET scanning in cancer. He has also played an active role in the development of local consumer research panels (CRPs) and has chaired the North Trent Consumer Research Panel since 2007.

On taking up the appointment, David said "I would like to see an effort made in the near future to produce a comprehensive map of consumer involvement in the cancer world. I would seek to use the expertise of the CLG membership to help make this a reality. It is important that we critically evaluate collaborative working to ensure that consumer involvement really is enhancing the quality of cancer research for patient benefit. There is a groundswell of support for consumer involvement at present that has been generated by the excellent work of our predecessors. We must ensure that this legacy is exploited to the full. I believe that local research panels have a massive role to play in future, and will seek to campaign actively for their proliferation. I believe that meaningful local experience will help to generate high quality national involvement."

Late Phase Trials Forum

26 June saw NCRI host the second Late Phase Trials Forum of the Experimental Cancer Medicine Centres (ECMC) Network

The morning session featured talks from clinicians and industry representatives on the issues and challenges of the Phase 2/3 transition. In the afternoon delegates attended workshops on the challenges for biomarkers in Phase 3 trials, translational research in surgical cancer trials and the role of research nurses in late phase trials. Attended by over 100 delegates, including research nurses, consumers, data managers, clinical

researchers and representatives from industry and funding organisations, the feedback highlighted the quality of the talks and the value of the networking lunch as well as the extended discussion time in the workshop sessions.

The next Early and Late Phase Clinical Trials Forums are to be held on 15 January 2009 and 25 June 2009 respectively. Further details of these meetings will be posted on www.ncri.org.uk/ctf as they become available. To express an interest in attending the meetings please email us at forum@ncri.org.uk.

Launch of the National Cancer Intelligence Network (NCIN)

The National Cancer Intelligence Network (NCIN) brings together people and organisations to provide a repository of cancer data to drive service improvement and to support research

The network, which has cancer registries at its heart, was formally launched on 18 June at a conference in London. Keynote speakers included Harpal Kumar, Chief Executive of Cancer Research UK, who focused on the epidemiological and health services research opportunities provided by NCIN, and Roger Boyle, National Director for Heart Disease and Stroke, who described the process and impact of publishing clinical outcome data in cardiac surgery, as a model. A series of presentations then described the "data journey" in detail, from collection, collation, feedback of findings and research uses. These were followed by parallel sessions on the uses of data for commissioning, service improvement and research.

NCIN data is already being used extensively and statistics on incidence and mortality by cancer network in England (2005) have been published. An on-line cancer map - the National Cancer eAtlas - provides a breakdown of incidence and mortality by local authority and figures on survival by cancer network for the most common cancers in England. Regional data can be filtered and easily compared to help with local decision making. A cancer commissioning toolkit (CCT) has recently been established with the National Cancer Action Team and is now being rolled out for use across the networks.

For more information on NCIN, visit www.ncin.org.uk.



International cooperation in cancer informatics



The 2nd joint conference between the NCRI Informatics Initiative and the US National Cancer Institute entitled "Biomedical Informatics Without Borders" was held in Bethesda, Maryland on 2 - 3 September

The event, attended by over 450 delegates, received much praise for the quality of the presentations, posters and discussion sessions. About half the presentations and posters were UK-based and half US-based and it was clear that there is great synergy between caBIG™, the cancer biomedical informatics grid that is being developed by NCI, and the NCRI Informatics Initiative's platform. The close working was particularly exemplified by a joint presentation from a UK/US project team that are working towards expanding current capabilities to create a global tool for cancer imaging, with UK and US project team members illustrating each other's progress.

Themes which emerged from discussion at the Conference included:

- The importance of data standards to enable sharing;
- The need for a pragmatic approach to the legal issues associated with data sharing and the importance of scientists being willing to share their data, adopt new technology and utilise standards;
- The need for technologists to understand the way scientists work to ensure that robust, user-friendly tools are developed;
- The need to integrate research and clinical care to improve the efficiency of translational research;
- How shared data can be used by publishers, libraries and software developers to diversify its use and extend its potential.

Further annual meetings are planned to build on the success of the first two. For more information on the NCRI Informatics Initiative, visit www.cancerinformatics.org.uk

NCRI Cancer Conference 5-8 October 2008

Now in its fourth year, the NCRI Conference has become a firm fixture in the calendar

Next month we will again welcome over 1500 delegates to the International Convention Centre in Birmingham to hear about all aspects of cancer research from molecular biology to therapeutic trials and end-of-life care.

Catering for all disciplines and career stages is a challenge, and we aim to respond to feedback from delegates so that we can develop the conference in new ways each year. This year

we will have proffered paper sessions for the first time, and have also introduced a new networking event for clinicians and industry representatives.

Suggestions for the Conference from the research community are welcome at all times and may be sent to info@ncri.org.uk. Please bear in mind that the planning lead-time is 12-18 months, so that ideas that come forward now will be considered for the 2010 event. <http://www.ncri.org.uk/ncriconference/>

National Prevention Research Initiative Phase 2 awards announced

Awards for Phase 2 of the National Prevention Research Initiative (NPRI) were announced during the summer.

The NPRI, born out of the 2004 NCRI report on Prevention and Risk Research, targets behavioural and lifestyle factors affecting the risk of cancer and other diseases including heart disease and diabetes. Phase 2 of the initiative focussed on use of existing datasets to understand determinants of behaviour, and the role of incentives in behaviour change. The funding partners have awarded £3m for 14 projects which address diet, physical activity, tobacco use and alcohol misuse.

An expanded consortium of 16 Funding Partners have also committed up to £12m over five years to support NPRI Phase 3. Launched in June 2008, this will again focus on behaviours associated with significant risks to health and in particular on the environmental factors that influence those behaviours. Research will aim to improve health and prevent diseases or conditions such as cancer, heart and circulatory diseases, diabetes, obesity, stroke and dementia.

Abstracts from all the successful Phase 1 and 2 awards, in addition to further information about Phase 3 are available at www.npri.org.uk

Awards made to fund research on the Supportive and Palliative Care (SuPaC) needs of Lung Cancer patients

In 2006, the NCRI Report on Lung Cancer Research in the UK highlighted the need to strengthen research on the supportive and palliative care requirements of lung cancer patients

Dedicated funds of £2.25m were pledged by seven NCRI partners to support a call for proposals in this area. The Partners decided to target the call to two broad research areas; (1) Symptom management with a focus on improving the patient experience and (2)

Studies aimed at assessing the effectiveness of different service models for patients in follow-up. Nine projects have been funded, based around the UK in both hospitals and in the primary care setting.

Details of the projects and funders can be found at www.mariecurie.org.uk/forhealthcareprofessionals/palliative_care_research/NCRISupportive-andPalliativeCareResearchCollaboratives/NCRI+Lung+Cancer+SuPaC+Research+Award.htm