

Strict embargo: 00:01 hrs  
Wednesday 18 June, 2008

## **NHS DATA 'POWER HOUSE' HARNESSSED TO DRIVE CANCER SERVICES AND RESEARCH**

THE National Cancer Intelligence Network (NCIN) launches today, which will bring together millions\* of NHS cancer records to create the largest patient-based cancer research resource in the world.

The NCIN will have access to the world's most complete source of cancer data from a whole population. The project will harness the power of the NHS and the cancer registries to enable researchers to study more comprehensively than ever before the impact of cancer.

Currently, data collection focuses on recording diagnoses and deaths from cancer. By building the largest collection of patient data in the world, the NCIN aims to better understand the cancer journey of each individual patient. This anonymised data will be used to raise the standards of cancer care by pinpointing areas of cancer services that need improvement.

Within a year, the NCIN will produce new and original figures on cancer – for example on cancer in different ethnic groups, teenagers with cancer and one-year cancer survival rates.

The £4m project, which will be overseen by the National Cancer Research Institute (NCRI), has been launched today at a conference attended by over 400 delegates from across the UK. At the launch, the first results will be presented – cancer incidence and mortality rates for each of the 30 Cancer Networks in England – and a new, publically available Cancer E-Atlas\*\*.

Professor Mike Richards, the Government's national cancer director, for England said: "The establishment of the NCIN was announced in the 2007 Cancer Reform Strategy, with the aim of creating the best cancer information system in the world by 2012.

“The NCIN will scrutinise aspects of cancer that are poorly understood, helping to improve understanding of the disease and patient outcomes.”

The NCIN will merge anonymised individual patient data from cancer registries, hospitals and NHS data sets, initially focusing on England but with a view to integrating data sets from across the UK. Information that is already generated by teams of cancer specialists as part of ongoing patient management, but not routinely reported or collated into a more powerful resource by the NHS, will now be gathered and analysed by the network.

This enriched data source will serve three main uses. It will enable researchers to make more detailed studies of trends in cancer to understand the risks and causes of the disease. Further analysis, including international comparisons of the data, will enable policy and decision-makers to pinpoint aspects of cancer services that need improvement, and to check if current policies are taking us in the right direction. And eventually it will allow people to compare cancer services in different areas and enable patients to make informed choices about where they are treated.

The NCIN is currently funded by the Department of Health, Cancer Research UK, Macmillan Cancer Support, Breakthrough Breast Cancer, the Medical Research Council, the National Institute for Health Research National Cancer Research Network and onCore UK. Once the NCIN is fully operational, funding for research projects will be provided by a range of other funders through normal scientific peer-review processes.

Harpal Kumar, Cancer Research UK’s chief executive, said: “The NCIN is an exciting project that takes advantage of the uniqueness of the NHS to drive improved outcomes in cancer. This is a project that would be virtually impossible anywhere else in the world. Cancer Research UK is delighted to be involved.”

Head of the NCIN, Chris Carrigan, said: “This initiative will bring us an invaluable amount of information on the journey of each cancer patient. Monitoring treatments

and patterns of care given to an individual patient is vital in helping us understand how best to deliver cancer services in the future.

“Looking at this individual analysis on a national scale will highlight which areas have the best outcomes for people with cancer.”

As the project develops, the NCIN will make an increasing volume of information available to the public, cancer patients and their families, providing vital information to help them make informed choices on where they are treated. This will be in collaboration with other initiatives, such as NHS Choices.

Professor Sir Alex Markham, chair of the NCIN and the NHS Research Capability Programme, and professor of medicine at the University of Leeds, said: “As we approach the 60th anniversary of the NHS, we’re beginning to use its power as an important research tool.

“The data that the NCIN will generate will allow us to draw information from cancer service provision that has previously been untapped. Crucially, we will also gain a more accurate understanding of mortality rates, as we will now more usefully capture data on how far the cancer has progressed when the disease is diagnosed.”

## **ENDS**

For media enquiries please contact the NCIN press office on 020 7061 8300 or, out-of-hours, the duty press officer on 07050 264 059.

### **Notes to editors:**

\* Around 22 million cancer records will be brought together by the NCIN, including records of multiple treatments for each cancer patient.

\*\* The Cancer E-Atlas be available from 7 July 2008 at [www.eAtlas.cancer.nhs.uk](http://www.eAtlas.cancer.nhs.uk)

### **About the National Cancer Research Institute (NCRI)**

The National Cancer Research Institute (NCRI) was established in April 2001. It is a partnership between government, the voluntary sector and the private sector, with

the primary mission of maximising patient benefit that accrues from cancer research in the UK through coordination of effort and joint planning towards an integrated national strategy for cancer research. [www.ncri.org.uk](http://www.ncri.org.uk)

The NCRI consists of: The Association of British Pharmaceutical Industry (ABPI); The Association for International Cancer Research; The Biotechnology and Biological Sciences Research Council; Breakthrough Breast Cancer; Breast Cancer Campaign; Cancer Research UK; CHILDREN with LEUKAEMIA, Department of Health; Economic and Social Research Council; Leukaemia Research Fund; Ludwig Institute for Cancer Research; Macmillan Cancer Support; Marie Curie Cancer Care; The Medical Research Council; Northern Ireland Health and Personal Social Services Research & Development Office; Roy Castle Lung Cancer Foundation; Scottish Executive Health Department; Tenovus; Wales Office of Research and Development for Health & Social Care; Wellcome Trust; and Yorkshire Cancer Research.

### **About the National Cancer Intelligence Network (NCIN)**

The NCIN will coordinate the collection, analysis and publication of comparative national information on diagnosis, treatment and outcomes for types of cancers and types of patient, in a way which is useful to patients, commissioners and service providers and other interested parties. As part of the NCRI, partners will help fund research on the data collated by the NCIN, facilitating a more informed analysis of cancer services than has ever been possible before. For more information visit [www.cancer.nhs.uk/ncin](http://www.cancer.nhs.uk/ncin)