

PRESS RELEASE

Friday 19 June, 2009

NCRI LAUNCHES TEMPLATE FOR SHARING RESEARCH DATA AND SAMPLES

The National Cancer Research Institute (NCRI) has launched a broad policy template on sharing research data and biological samples, which will help to streamline the governance requirements for biomedical research which uses such resources.

Working in partnership with the National Cancer Intelligence Network (NCIN) and onCore UK, the NCRI have produced a "how-to" guide for custodians of databases and biobanks to assist them in developing their own policies for deciding on how to grant other researchers access to important research resources they hold.

The template will help them to ensure that their data and sample sharing policies are legal, ethical and effective.

Reducing unnecessary duplication of data and sample collection by sharing more effectively will help to ensure that public money and charitable funds are used in the most efficient way, and it will speed up research to benefit patients.

Professor Sir Kenneth Calman, chair of NCRI, said: "The creation of an access policy can be daunting; it is often easier to say no to sharing, and avoid the difficulty, than to venture to say yes. But there is a great deal to be gained if we can all say yes more often."

The guide will also help to ensure that researchers seek informed consent when collecting data and samples, so that they can be securely shared with other researchers at a later date, if desired.

Mr David Ardron, chair of the NCRI Consumer Liaison Group, which brings together people who have been affected by cancer to consult with cancer organisations on research issues, said: "When we ask them, cancer patients are often surprised or even dismayed by how little use we make of their samples and information.

Where patients agree to it, we have an ethical duty to generate the most knowledge possible from the data and samples they provide."

The template is written so that each organisation can adopt or adapt points that are relevant to their circumstances, ensuring that any policy developed, reflects best practice in a consistent manner.

Although organisations can modify the terms in the template to suit their needs, greater consistency between access policies will help to encourage researchers to share samples and data with the confidence that they do so in a way that is consistent with regulatory requirements.

Mr Chris Carrigan, head of the NCIN, said "The goal of this document is to enable the responsible sharing of data and samples for the benefit of all: patients, the public and researchers."

Dr Brian Clark, chief executive of onCore UK, said: "This template will be a very welcome tool for those running biobanks. It has helped onCore UK develop its own Access Policy and will be useful when advising others in the field to develop or revise their own policies. It is clearly written, easy to use and authoritatively deals with the issues that must be considered when providing access to samples and data. Furthermore, having been prepared after wide consultation it reflects a broad consensus of opinion and current best practice."

NCRI is looking for organisations to pilot use of the template and give feedback on it, so that it can be improved in the light of experience. It will also be updated in response to any regulatory changes.

To obtain a copy of the template, go to <http://www.ncri.org.uk/default.asp?s=1&p=8&ss=9>

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For media enquiries please contact Rachel Gonzaga in the Cancer Research UK press office on 020 7061 8252 or, out-of-hours, the duty press officer on 07050 264 059.

About the NCRI

The National Cancer Research Institute (NCRI) was established in April 2001. It is a UK-wide partnership between the government, charity and industry which promotes

co-operation in cancer research among the 21 member organisations for the benefit of patients, the public and the scientific community. NCRI members are: the Association of the British Pharmaceutical Industry (ABPI); Association for International Cancer Research; 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; Ludwig Institute for Cancer Research; Macmillan Cancer Support; Marie Curie Cancer Care; Medical Research Council; Northern Ireland Health and Social Care (Research & Development Office); Roy Castle Lung Cancer Foundation; Scottish Government Health Directorates (Chief Scientist



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Office); Tenovus; Welsh Assembly Government (Wales Office of Research and Development for Health & Social Care); The Wellcome Trust; and Yorkshire Cancer Research.

About the NCRI Consumer Liaison Group

The CLG operates to improve the quality and value of cancer research through consumer involvement and to raise public awareness of clinical research and cancer research in particular.

The CLG brings together individuals with personal experiences of cancer including patients, carers and relatives as well as representatives of cancer support organisations, researchers and other professionals with an interest in consumer involvement in cancer research as part of their roles.

About the National Cancer Intelligence Network (NCIN)

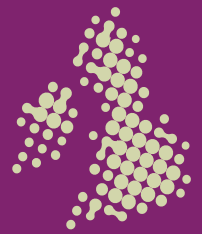
- The NCIN was established in June 2008 and its remit is to coordinate the collection, analysis and publication of comparative national statistics on diagnosis, treatment and outcomes for all types of cancer
- As part of the National Cancer Research Institute, the NCIN aims to promote efficient and effective data collection at each stage of the cancer journey
- Patient care will be monitored by the NCIN through expert analyses of up-to-date statistics
- The NCIN will drive improvements in the standards of care and clinical outcomes through exploiting data
- The NCIN will support audit and research programmes by providing cancer information
- The NCIN receives the bulk of its funding through the NHS

National Cancer Action Team

- Visit www.ncin.org.uk for more information

About onCore UK

- onCore UK is a charitable organisation working within the NCRI that serves as a national action team to inform, coordinate and develop cancer biobanking for the benefit of advancing cancer research.
- onCore UK complies with all applicable regulation in the UK including the Human Tissue Act and the Data Protection Act 1998.
- onCore UK was founded through a collaborative funding partnership with the Department of Health (England), the Medical Research Council (MRC) and Cancer Research UK in 2005.
- To find out more, visit www.oncoreuk.org.



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