

**Cancer Research UK response to National Information Governance Board Guidance
on the amendment of medical and social care records following a request from a
person receiving care**

September 2009

Introduction

Cancer Research UK greatly welcomes the opportunity to respond to this consultation. Cancer Research UK funds research into all aspects of cancer from exploratory biology to clinical trials of novel and existing drugs as well as population-based studies and prevention research. In 2007-08 we spent over £13m supporting research using patient data alone.

Access to patient data is especially important in cancer. Epidemiological research is pivotal to our understanding of cancer as a disease, in a way that is not true for many other conditions. As half of cancers are potentially preventable, patient data have been especially important to help identify some of the factors that put people at risk of cancer in the first place.

We are responding to this consultation as funders of medical research that uses patient data, and as such we are only submitting comments on the section entitled 'Use of health information from records for purposes other than for the provision of care and treatment'.

We agree that the primary care records should not be altered after the time of writing without full annotation of the record clarifying how and why it was altered. The suggestions that are outlined in the guidance document surrounding records that are within systems used solely for secondary purposes are logical. We would support further guidance and clarification on this topic from the Information Centre for Health and Social Care. In addition, we would support clear guidelines for researchers to become available detailing procedures in place when care records are altered, and the impact on the use of that data for secondary purposes.

We hope you find our comments useful. We are very keen to continue to work with the National Information Governance Board and the Ethics and Confidentiality Committee as they develop their work around the use of patient data in research.

We would be happy to provide any further information or detail as required. Please contact Emma Greenwood, Science Policy Researcher at Emma.Greenwood@cancer.org.uk or on 0207 061 8358.

**Cancer Research UK
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