

Jenny Harper  
Department of Health  
Wellington House  
135-155 Waterloo Road  
London SE1 8UG

21<sup>st</sup> June 2007

Dear Ms Harper,

**Cancer Research UK response to the Department of Health Consultation-  
Review of parts 2, 5 and 6 of the Public Health (Control of Disease) Act 1984**

Cancer Research UK<sup>1</sup> is the world's largest independent organisation dedicated to cancer research, with a research spend of over £257 million in 2005/6. Our vision is that together we will beat cancer. Cancer Research UK welcomes the opportunity to respond to this consultation.

**Cancer Research UK would welcome measures to make cancer a statutorily reportable condition.**

Reliable cancer registration is essential to monitor the impact of the Cancer Plan for England, the forthcoming Cancer Reform Strategy and other public health and cancer policies, to evaluate service provision, assess unmet need, and to provide vital data for population-based cancer research.

Complete data are critical for the detection of any significant correlation in studies. If cases are missing, the data can be skewed and consequently miss significant effects. For example, as things currently stand, it will be difficult to tell if a future fall in cervical cancer incidence following HPV vaccination is due to the vaccine or an increasing level of opt-outs over time.

Population coverage is most important for disease registries<sup>2</sup>. Comparative international evidence highlights that full and complete registration is not possible under a system of explicit consent<sup>2,3,4</sup>. Seeking consent to use data for research raises the issue of self-selection bias amongst data subjects. There is good evidence of differences between individuals who consent to participate in research and those

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<sup>1</sup> Registered charity no. 1089464

<sup>2</sup> Ingelfinger JR & Drazen JM Registry research and medical privacy N Eng J Med 2004; 350:1542–1543

<sup>3</sup> Tu JV, Willison DJ, Silver FL, Fang J, Richards JA, Laupacis A et al. Impracticability of informed consent in the Registry of the Canadian Stroke Network. N Eng J Med 2004; 350:141–142

<sup>4</sup> McKinney PA, Jones S, Parslow R, Davey N, Darowski M, Chaudhry B et al A feasibility study of signed consent for the collection of patient identifiable information for a national paediatric clinical audit database. BMJ 2005; 330:877–879

who do not<sup>5</sup>. We therefore believe that statutory cancer registration would best fulfil public health responsibilities.

In addition, there is evidence to show that individuals do not consider the collection of details from cancer patients to help research an invasion of their privacy. A Cancer Research UK funded study, conducted by Professor Michel Coleman, published in 2006<sup>6</sup>, reported that 80% of the British public would support legislation to make cancer registration compulsory.

We hope that you will consider introducing measures to develop a notification system for non-communicable diseases and we would be happy to be consulted on more detailed cancer proposals. It is essential that any system collects data in a uniform way and has built-in quality assurance.

Yours sincerely,

A handwritten signature in black ink that reads "Richard Davidson". The signature is written in a cursive, slightly slanted style.

**Richard Davidson**  
**Director of Policy and Public Affairs, Cancer Research UK**

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<sup>5</sup> Al-Shahi R, Vousden C & Warlow C Bias from requiring explicit consent from all participants in observational research: prospective population based study 2005 BMJ 331:942

<sup>6</sup> Barrett G, Cassell JA, Peacock JL, Coleman MP. National survey of British public's views on the use of medical data by the National Cancer Registry. BMJ, May 2006; 332: 1068–1072