

Sean Doohan
Scottish Executive Health Department
Public Health Team
3E(S) St Andrew's House
Regent Road
Edinburgh
EH1 3DG

5th January 2007

Dear Mr Doohan,

Cancer Research UK response to the Scottish Executive Consultation- Public Health Legislation in Scotland: A Consultation

Cancer Research UK¹ is the world's largest independent organisation dedicated to cancer research, with an annual research spend of over £257 million. Our vision is that together we will beat cancer.

Cancer Research UK welcomes the opportunity to respond to this consultation. Our response focuses on question 2.2, on proposals to develop an additional notification system for non-communicable diseases that:

- a) defines the "statutory reportable conditions";
- b) places a statutory duty on public and private sector organisations involved in caring for individuals suffering from the disease or investigating its extent in a population to report on a regular basis the numbers and details about those suffering from the disease and specified factors involved in its causation;
- c) specifies the diseases and the details required or the specific measurable factors leading to their occurrence to be reported;
- d) does not require consent for notification since it will be a legal requirement to notify and report;
- e) specifies a time limit for notification and reporting in regulations; and
- f) specifies a penalty for not notifying in regulations.

Cancer Research UK is supportive of the proposals and would welcome measures to make cancer a statutorily reportable condition.

Reliable cancer registration is essential to monitor the impact of the Scottish Cancer 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, so, miss significant effects.

¹ Registered charity no. 1089464

Population coverage is most important for disease registries². Comparative international evidence highlights that full and complete registration is not possible under a system of explicit consent^{2,3,4}. 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 who do not⁵. 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 2006⁶, reported that 80% of the British public would support legislation to make cancer registration compulsory.

We hope that you will take forward proposals to develop a notification system for non-communicable diseases and 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,



Professor John Toy
Medical Director, Cancer Research UK

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

³ 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; 350:141–1421

⁴ 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

⁵ 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

⁶ 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