

13 June 2011

## **Re: Improvements to the New Zealand Cancer Registry**

On 31 March 2011 the Commissioner received a letter from Professor David Lamb, Associate Professor Chris Atkinson, and Mr Andrew Bridgman, seeking his feedback on the proposed changes to the New Zealand Cancer Registry. He was asked to bring his comments to your attention.

I have discussed the letter with the Commissioner, and provide his comments as follows. The Commissioner commends the work of Cancer Control New Zealand to enhance the value of the New Zealand Cancer Registry (the Registry) for New Zealanders. He supports the four major recommendations made by the international review panel following the external review of the Registry in 2010, with the following additional comments:

### *Cancer registry governance*

The Commissioner suggests consumer input at the governance level. The recommendation from the external review was for a “sector focused” governing body whose primary role is to champion further development of the Registry by helping to define it’s vision and expectations, and by ensuring that the day-to-day management follows those overarching goals.

To be “sector-focused” the Board must allow for consumer input. This is particularly important given that the Registry is one of the few examples where the right to give consent is waived in the interest of the public good. Consumer input will ensure a patient-centered approach, which is important both now as the Board develops and implements changes to the Registry in accordance with the external review recommendations, as well as for long-term program input.

### *Collection of basic clinical data on all cancer registrations*

The Commissioner supports the inclusion of basic clinical data, such as staging and recurrence, on the Registry. Including this data for quality improvement and evaluation of the screening program, treatment planning and clinical management is an important development in the Registry and consistent with the purposes of the Registry as defined in section 4(2) of the Cancer Registry Act 1993.

However, the Board needs to remain cognizant that the Registry operates on an exception to the general rules regarding individual consent. The points at which clinical stage information are to be collected, and the type of information collected, should be carefully defined and

regulated to ensure continuing appropriate protection, in accordance with the Registry's current practices, and legal and ethical safeguards.

*Improving the accessibility of Registry data*

The Commissioner notes the proposal that data held on the Registry be made accessible to both medical practitioners and health planners. Medical practitioners will be able to view data on their own patients and find out baseline data on individual cancers. Health planners will be able to view contemporary data on cancer demographics in New Zealand so effort and expenditure can be focused on the areas of greatest need.

It is important for the Board to ensure any changes to the accessibility of Registry information does not undermine current legal and ethical safeguards for access to, and use of, that information.

We are happy to provide further comments on any future planning documents developed by the Board for the implementation of the external review recommendations.