A response to: Characteristics of lung cancers and accuracy and completeness of registration in the New Zealand Cancer Registry

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Professor Ross Lawrenson's paper highlights the value of the New Zealand Cancer Registry (NZCR), which has been in existence since 1948, as the most complete record of cancer diagnoses in New Zealand. The paper also provides clear evidence for improvements: in particular, collecting clinically diagnosed cancer and clinical group stage through the NZCR. The American Joint Committee on Cancer (AJCC)'s international staging guidance highlights that clinical group stage should be assigned by the clinician managing a patient's care and treatment.

Reporting to the NZCR is mandated under the Cancer Registry Act 1993 (the Act) and registrations are made in accordance with International Agency for Research on Cancer (IARC) guidelines. The Act requires a report to be made when a laboratory test indicates the presence of cancer. It does not enable reporting from other medical practitioners, such as radiation oncologists, and NZCR staff only have access to coded hospital discharge summaries, pathology reports and death certificates.

Lawrenson et al identifies that the NZCR is population-based, focusing on incidence data, and states the purposes of the NZCR from the Act (information on incidence and mortality, and informing survival studies and research). His point that “[the NZCR's] completeness and accuracy are vital for cancer control in New Zealand” implies his research revealed a lack of completeness and accuracy. However, the NZCR is complete and accurate to the extent its enabling legislation allows. There is no ability in the Act or accompanying Cancer Registry Regulations 1994 for NZCR staff to require further or more information. As a population-based registry operating in accordance with international rules, the focus on incidence is appropriate.

Analysis of the NZCR's lung cancer data from 2011–2015 by the Ministry demonstrates that the under-reporting of lung cancers in the NZCR for this study were approximately 1% of cases, rather than the 4% reported in the paper. Reasons for the variation include:

- Differences in coding rules—IARC classifies carcinoid tumours as malignant unless specified as benign. This accounts for a significant proportion of the registrations deemed by the research group as ‘not lung cancer’
- Differences in defining ‘date of diagnosis’—NZCR is a dynamic registry that is updated as new information is received. Some of the ‘missing in NZCR’ lung cancers were registered in NZCR after the study data was extracted, and others had registration dates before or after the study period
- Duplicates versus two distinct primary tumours in the same individual—if the morphological type of a second cancer is different to that of the first cancer then both are registered (in accordance with the Berg Group rule).

The Ministry of Health Cancer Services team has a focus on enabling quality
improvement that supports nationally consistent access to treatment and equity of outcomes across population groups and geographical boundaries. National administrative service delivery data can be linked to population-based registries such as NZCR data to report on system-wide performance measures. The Lawrenson et al audit highlights some of the limitations of this approach.

Roder et al identify strengths of population-based registries and their corresponding limitations for driving quality improvement in service delivery. There is a clear need for data such as clinical group cancer stage and other prognostic indicators to be added to the NZCR. More detailed information necessary to drive quality includes surgery, pathology, chemotherapy treatment regimes, radiology, multidisciplinary meetings and clinical trial participation.

We consider that a more flexible, responsive approach is required to meet the needs of our rapidly changing health environment. This includes reviewing the Act and developing and agreeing structured reporting with service providers. We are mindful that any change needs to take into account the availability of data in patient management systems, and readiness of providers to contribute additional data.

**REFERENCES:**
