

Development of a Bi-National Thyroid Cancer Clinical Quality Registry

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Abstract : Background: The occurrence of thyroid cancer is increasing throughout the developed world, including Australia and New Zealand, and since the 1990s has become the fastest increasing malignancy. Following the success of a number of institutional databases that monitor outcomes after thyroid surgery, the Australian and New Zealand Endocrine Surgeons (ANZES) agreed to auspice the development of a bi-national thyroid cancer registry. Objectives: To establish a bi-national population-based clinical quality registry with the aim of monitoring and improving the quality of care provided to patients diagnosed with thyroid cancer in Australia and New Zealand. Patients and Methods: The Australian and New Zealand Thyroid Cancer Registry (ANZTCR) captures clinical data for all patients, over the age of 18 years, diagnosed with thyroid cancer, confirmed by histopathology report, that have been diagnosed, assessed or treated at a contributing hospital. Data is collected by endocrine surgeons using a web-based interface, REDCap, primarily via direct data entry. Results: A multi-disciplinary Steering Committee was formed, and with operational support from Monash University the ANZTCR was established in early 2017. The pilot phase of the registry is currently operating in Victoria, New South Wales, Queensland, Western Australia and South Australia, with over 30 sites expected to come on board across Australia and New Zealand in 2018. A modified-Delphi process was undertaken to determine the key quality indicators to be reported by the registry, and a minimum dataset was developed comprising information regarding thyroid cancer diagnosis, pathology, surgery, and 30-day follow up. Conclusion: There are very few established thyroid cancer registries internationally, yet clinical quality registries have shown valuable outcomes and patient benefits in other cancers. The establishment of the ANZTCR provides the opportunity for Australia and New Zealand to further understand the current practice in the treatment of thyroid cancer and reasons for variation in outcomes. The engagement of endocrine surgeons in supporting this initiative is crucial. While the pilot registry has a focus on early clinical outcomes, it is anticipated that future collection of longer-term outcome data particularly for patients with the poor prognostic disease will add significant further value to the registry.

Keywords : thyroid cancer, clinical registry, population health, quality improvement

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