

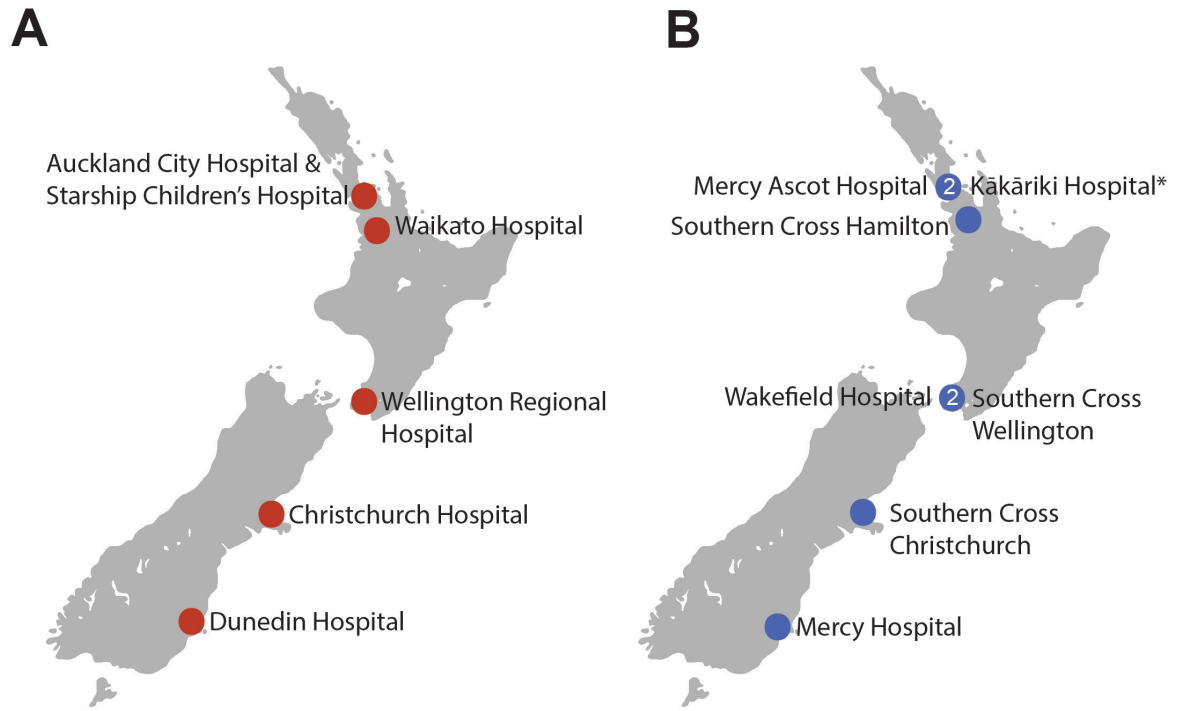
Table 1: Summary of selected clinical registries in New Zealand, outlining key characteristics and lessons that may be useful in the establishment of a national brain tumour registry.

Registry	Key characteristics	Key lessons
New Zealand Cancer Registry (NZCR)	<p>A government registry of all primary cancers diagnosed in New Zealand, functioning under the <i>Cancer Registry Act 1993</i>, which mandates the reporting of cancer cases.⁴</p> <p>Gathers incidence and mortality data on all patients diagnosed with cancer (excluding non-melanoma skin cancer).</p>	<p>Data on secondary brain metastases and benign tumours are not collected; lobbying to include this information would be required if the NZCR data were to be relied on.</p> <p>Data on treatment and non-fatal outcomes are not collected; additional information would be required if the NZCR data were to be relied on.</p>
New Zealand Breast Cancer Foundation National Register (NZBCFNR)	<p>Established in 2018 when four regional registries, each with their own governance groups, were amalgamated.⁶</p> <p>Funding from Breast Cancer Foundation New Zealand.</p> <p>Near 100% coverage of eligible breast cancer patients in New Zealand, increased from 63% prior to amalgamation.⁶</p> <p>Aims to use data to reduce inequities, improve patient outcomes and monitor progress through the provision of breast cancer data to clinicians, health workers and researchers.⁶</p> <p>Opt-out model of consent.</p>	<p>Such a comprehensive registry requires a team of data managers throughout the country to manually manage data collection.⁶</p> <p>100% coverage can be achieved with an opt-out consent model (opt-out rate <1%).⁶</p> <p>A regional registry structure is unlikely to cover the entire patient population of interest.</p> <p>The NZCR can be used to validate datasets.</p> <p>Charities and advocacy groups can be an effective and important resource for expertise and funding opportunities.</p>
Prostate Cancer Outcomes Registry Australia and New Zealand (PCOR-ANZ)	<p>An Australia and New Zealand registry focussed on patient outcomes.</p> <p>The Movember Foundation invited groups to express their interest in establishing state prostate cancer registries in 2013.¹¹ New Zealand was recruited in 2015.¹¹ Each regional register has their own governance structures.¹¹</p> <p>Substantial funding from the Movember charity allowed the project to get underway.¹²</p> <p>State-based registries submit data to the national registry. Population coverage is 59% across Australia and 78% across New Zealand.¹²</p> <p>Opt-out model of consent.</p>	<p>Collaboration with neighbouring countries can facilitate registry implementation through greater access to resources.</p> <p>Multi-tiered, complex registry structures are slower to implement and slower to reach full coverage.</p> <p>Charities and advocacy groups can be an effective and important resource for expertise and funding opportunities.</p>

Table 1 (continued): Summary of selected clinical registries in New Zealand, outlining key characteristics and lessons that may be useful in the establishment of a national brain tumour registry.

<p>New Zealand Trauma Registry (NZTR)</p>	<p>A database of every major trauma patient admitted to acute hospitals across New Zealand.^{8,9}</p> <p>Data collection dating back to 2015.⁸</p> <p>Sponsored by the Ministry of Health and the Accident Compensation Corporation (ACC).⁸</p> <p>A single, web-based website for data entry by clinicians and data managers.⁸</p> <p>Opt-out model of consent.</p>	<p>A close relationship with government bodies can help fast-track initiatives.</p> <p>A close relationship with all participating centres is vital for buy-in.</p> <p>A simple registry structure and relatively small minimum dataset can still yield strong, valuable data.^{8,9}</p>
<p>New Zealand Children's Cancer Registry (NZCCR)</p>	<p>A paediatric cancer registry established in 2000 that collects demographic, diagnostic and treatment information.¹⁰</p> <p>Under the governance of the National Child Cancer Network (NCCN).</p> <p>Data collected from the two specialist paediatric oncology centres in New Zealand.¹⁰</p> <p>Collaborate with the Late Effects Assessment Programme (LEAP) national database for comprehensive chemotherapy, radiotherapy and long-term follow-up details.¹⁰</p> <p>Both malignant and non-malignant paediatric brain tumours are included.</p> <p>Opt-out model of consent.</p>	<p>Targeting the specialist clinical centres allows for accurate data collection without involving every hospital across New Zealand.</p> <p>Collection of data on non-malignant brain tumours can be achieved.</p> <p>Can use the NZCR and Mortality Collection to validate cancer cases.</p> <p>The use of existing registries, government structures and databases can prevent unnecessary data duplication and provide supplementary information.</p>

Figure 1: Locations of the **A)** five Te Whatu Ora – Health New Zealand and **B)** seven private neurosurgical centres in New Zealand.



*Kākāriki Hospital is a new private hospital, opened in 2024.

Figure 2: The brain tumour patient pathway, which describes the progression of a brain tumour patient throughout New Zealand’s neuro-oncology system.

BRAIN TUMOUR PATIENT PATHWAY

