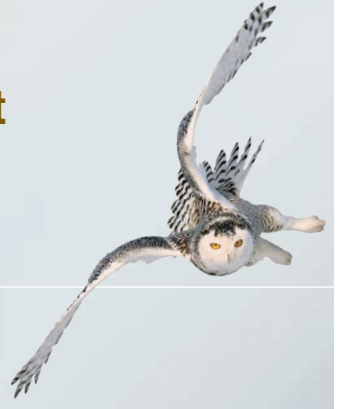


Evaluation of adolescent and young adult cancer services



<p>What we were asked to do</p>	<p>The Adolescent and Young Adult (AYA) National Network was aware of some issues with reported mortality outcomes for certain cohorts of young people with cancer in New Zealand, compared to international benchmarks. To address these issues an AYA key worker role was introduced to assist young people with adherence to treatment and any range of other aspects of their life with cancer.</p> <p>As part of four work streams, the network commissioned Sapere to undertake a two-pronged evaluation of the AYA Key Worker Roles in six cancer centres in New Zealand. This involved both a patient experience evaluation and a process evaluation, with interviews with key clinical and support bodies stakeholders. For the young people and families, the interviews were conducted one-on-one whereas for the other stakeholders, focus groups and joint interviews were used.</p>
<p>How we approached the project</p>	<p>The patient experience evaluation involved: interviewing adolescents and young people (or if they were under age 16 years, their guardians, for consent reasons) on their experiences of the cancer services and how they worked for them. Topics were sensitive (e.g. diagnosis, fertility) and being a “vulnerable” group (i.e. children) full National Health and Disability Ethics Committee approval was sought and granted. In addition local District Health Boards’ ethics committee permissions were sought and granted.</p> <p>The process evaluation involved interviewing:</p> <ul style="list-style-type: none">• the key workers themselves• key cancer related health professionals <p><i>continued over</i></p>

How we approached the project	<ul style="list-style-type: none">• experts• support groups (non-government organisations like Canteen). <p>The interviews were to ascertain views on the recently introduced key worker roles and to ascertain perceptions on whether there were any changes to adherence to treatment and/or health outcomes.</p>
Our findings	<p>Our report noted the enormous success of the key worker roles for the young people, however a need to support them better to ensure sustainability over time. Various recommendations were made and all adopted, including funding coming from Government to support them with in a short time frame, i.e. within the following quarter.</p>