

Conclusions

The existence of a comprehensive database with population capture has permitted a holistic overview of patterns of incidence, survival and health care utilization that mirror the reality of the entire childhood cancer population. The advantages of the population-based dataset are self-evident, more particularly in the context of the ability to link to other databases. This unique dataset has yielded insights into areas of key importance as we strive to improve the cancer journey for all children – in terms of not only survival rates, but also the quality of the journey.

Childhood cancer contributes a small proportion of incident cases – but a very large number of life years gained as a result of successful treatment. In distinction to adults with cancer, virtually all children with cancer are treated primarily at 1 of 5 Ontario Academic Health Sciences Centres, enabling accurate tracking of the diseases, treatments, outcomes and health care utilization.

The reader will, we hope, have a better perspective on childhood cancer issues, albeit a perspective that we believe can be improved by further research, which we hope readers will be interested in sharing with us – the database is available for use by qualified investigators with appropriate Ethics Board approval. It is our intent to publish updates on this cohort as it ages, but also to update the Atlas cohort with the next cohort, diagnosed between 2005 and 2009, as 5 year follow up becomes possible.

As demonstrated in the Incidence chapter, readers can be reassured that the incidence of cancer in children is not rising in Ontario, nor are there pockets of increased incidence at any location in the province. Of interest is the changing gender ratio for some tumours and the peculiar gender distribution for such tumours as Burkitt lymphoma and thyroid carcinoma – areas for further research.

The Survival chapter demonstrates the value of population capture, showing a clear overall steady increase in survival rates across all categories of malignancy. It also demonstrates that relapse of the primary disease, while devastating, is not a harbinger of fatality – survival rates are appreciable, albeit with very aggressive and resource-intensive therapy.

And overall, the diagnosis of childhood cancer invokes a resource use pattern that is intensive, stretching over long periods of active treatment. Beyond the period of active treatment, resource use for pediatric cancer patients remains log orders greater than for the general childhood population. The resource use captured in this Atlas does not account for the considerable resources necessary in pathology and molecular diagnosis, in diagnostic imaging or in any of the psychosocial disciplines – all of which are critical to accurate diagnosis, appropriate therapy and optimal long term outcomes, physical and emotional. It will be imperative, in our single payer health care system, for resources, in all disciplines and modalities, to match utilization to ensure not only the best survival rates, but survival with good quality of life and a journey made as tolerable as possible – a matter that the government has kept, and must continue to keep, top of mind as we produce an ever increasing population of survivors of childhood cancer.