

The Need for a Blood Cancer Registry

- Blood cancers are a significant public health issue because they constitute a major proportion of the years of premature life lost from cancer, and many of these diseases are potentially curable.
- The lack of national data detailing incidence, treatment patterns and outcomes for patients with these malignancies has been recognised for some time as an impediment to the delivery of optimal care.
- While central cancer registries in each state and territory provide excellent information on incidence, survival and mortality rates for blood cancers, there is not enough specific data on staging and treatment to guide clinical care.
- Because the blood cancer field is moving so rapidly timeliness and the level of detail of the classifications in the central cancer registries are also issues.
- The central cancer registries are not currently designed to monitor efficacy of treatment or evaluate the cost effectiveness of therapies - survival rates depend on the delivery of customised therapy which varies with disease stage and other prognostic factors.
- Most clinical haematologists believe that a more detailed national registry will improve the capacity to make informed and timely decisions on the diagnosis and management of patients with blood cancers, leading to better outcomes for patients, as well as enhanced government policy development and resource allocation.
- Concerned about the issue, representatives from health consumer organisations and clinical haematologists from around Australia met in 2004 to discuss ideas about developing a national haematology registry to capture the data needed.
- After extensive consultation and the development of a model, a meeting entitled Working Towards an Australian Blood Cancer Registry was held in Sydney on 30 September 2005. The meeting brought together a range of stakeholders to discuss building a national haematology registry with the dual aims of developing a clear agreed plan and recruiting key clinical champions to drive the process.
- It was agreed by all at the meeting that in a time of evidence-based medicine, clinical audits and patient empowerment in disease management, there was an overwhelming need for improved data collection around blood diseases.
- Two national workshops have been held since – these have resulted in a consensus position adopted by AIHW on classifications; an agreed minimum data set; the initiation of a project on structured pathology reporting for blood cancers and a successful and innovative project on the incidental electronic collection of data for a clinical registry
- **There is consensus among the stakeholders that a clinical registry for blood cancers is an essential tool in fighting these cancers** and that a sound business case could be developed to support this.

