

Who is involved?

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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. 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 and resource allocation.

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. Unanimous support for the development of the ABCR was received from 37 representatives of clinical, research, academic, consumer, support and government organisations, pathology laboratories, pharmaceutical representatives and software developers.

Enthusiastic and recognised experts have been recruited to the Project Management and Clinical Reference Groups to guide the ABCR development. Meetings are held on a regular basis and a governance framework has been established. The Project Management Group is chaired by Dr David Joske, Head - Department of Haematology, Sir Charles Gairdner Hospital, Perth.

A number of the State Cancer Registries are represented on the Clinical Reference Group. Work on a number of initiatives is being progressed in close association with the State Cancer Registries to build on existing resources.