

Further information on developing the ABCR

Contributed by Administrator
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What information will the ABCR collect?

The Australian Blood Cancer Register will identify each blood cancer and subgroup. Information on disease progression and treatment will be collected to provide information on staging and survival of the disease. Evaluating this information will allow comparison of treatment options, improved practice guidelines and help identify quality initiatives, prognosis indications, known risk factors and complications. The ABCR will build on existing resources and avoid duplication. The ABCR will protect personal information, and will be bound by Commonwealth legislation. Information gathered will be stored, analysed and reported on with all individual identifying details removed to ensure total security, confidentiality and anonymity and will be used for health research only.

Who will the ABCR help and how?

The ABCR will provide clinical haematologists and oncologists with accurate and detailed information to improve survival and treatment outcomes. Patients, family members and carers will benefit as the information will allow them to understand and choose their treatment options. In addition, government will be able to improve policy development, resource use and allocation and pharmaceutical companies will be able to improve medications.

How is it being funded?

The ABCR Project Management Group has received funding through the Information Technology Online Program (ITOL) of the Commonwealth Department Information and Communications Technology and the Arts to develop the Lymphoma Wizard (see specific section in the website). Additional support from a consortium of the Leukaemia Foundation, the Haematology Society of Australia and New Zealand, Sullivan and Nicolaidis Pathology (Sonic), Queensland Medical Laboratories (Symbion), Medical-Objects, Australian Leukaemia and Lymphoma Group (ALLG) and Roche Products has also been gained.

A number of organisations have suggested that they will provide considerable funding in the future. A program to identify and seek funding to support project development has been implemented.

Roche Products is the foundation sponsor of the Australian Blood Cancer Registry. It initiated this important project after identifying the need through wide ranging discussions with haematologists representing key professional and research organisations and teaching hospitals, in addition to consultations with various health consumer organisations. Roche continues to commit generous untied funding to facilitate the development of the ABCR.

What is the process?

To develop the ABCR the Project Management Group is working to implement key recommendations and outcomes identified by stakeholders at a meeting in September 2005. The stakeholder recommendations and outcomes were developed into specific initiatives and projects that can be identified, funded and actioned such as the Lymphoma Wizard. A one page plan outlining the strategic projects to implement the outcomes and recommendations of the Stakeholder meeting has been developed by the Project Management Group and is available on the Download information section of the website. Together these projects and initiatives will build to establish the ABCR. The ABCR stakeholders meet annually to review progress and provide advice.

What is the timeframe?

The ABCR will progress over a number of years as each of the initiatives and projects such as the Lymphoma Wizard are developed, established and implemented. Important information will be collected and built upon at each stage.