

*TITLE: The who, what, where, when and why of cancer information.*

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Hands up anyone who has heard of the NSW initiative to collect information about cancer. Are you aware of the Clinical Cancer Registries which have been set up in six of the eight Area Health Services in NSW? Do you know the difference between a Central Cancer Registry and a Clinical Cancer Registry? Where does the NSW Cancer Institute fit into the picture?

In one Area health service in NSW, the journey from nowhere to somewhere began in 2006 and is still ongoing. Initially the work was a 'proof of concept' project, staff were appointed, and a NSW central database was developed on which to amass the information.

In the current era one would think that data could be collected electronically. While the majority of information can be mined from electronic sources, manual data entry is still necessary and time consuming. Nonetheless it is essential to complete a picture of the cancer patient's journey from diagnosis, through the many and varied treatments, to outcome.

On investigation it transpires that paper medical records are still in daily use and many clinical information systems are designed to be stand-alone and function only for the purpose for which they were created.

Some of the best resources to undertake this work are Health Information Managers. Their skills, training and knowledge assist with achieving the end objective: accurate, timely and complete data.

This paper will: describe the setting up of a Clinical Cancer Registry; the challenges that the team faced; setting up a Cancer electronic medical record (EMR); and the possible merger of data with the NSW Central Cancer Registry. All of which will come together to ensure collection of good quality cancer data, that is fundamental to ensure that accurate information about diagnoses, treatments and outcomes is available to all clinicians and staff.