**Report on how legal obligations and data management affect the ability of the information systems to meet objectives for the Cancer Research Share-Net.**



La Trobe University would like to trial an intranet that allows the researchers at the La Trobe School of Cancer Medicine to access patient data from private cancer clinics. The intranet will be called the Cancer Research Share-Net.

The Olivia Newton John (ONJ) Cancer Wellness & Research Centre has agreed to be a part of the first trial. The ONJ Centre is a private clinic where patients are tested, treated and provided with palliative care.\* It is a not-for profit organisation but is operated as a private business.

La Trobe School of Cancer Medicine is both a research institute and a teaching and learning department of La Trobe University. Students at the School of Cancer Medicine are medical graduates who wish to learn more about cancer research and to endeavour to conduct research to publish for medical journals.

It became clear that medical research needs to have access to up-to-date data that describes the patient responses to the latest drug treatments. To ensure they have the data required to run the research, La Trobe will test an intranet that private clinics can access to provide all test results, treatment results and responses to drug and other palliative care treatments. Data is generated every day at each clinic. If researchers had access to the data in a timely manner they may be able to produce better research results that can assist medical practitioners.



At the ONJ Centre they have their own Information System called Med-Net. Nursing staff input patient personal details, (name, age, address, next of kin etc.) into Med-Net. Each patient has their own record. Nurses also update their medical records into Med-Net with the following data:

* Types of tests conducted – including date, details
* Test results
* Treatments
* Treatment results

Nurses may conduct tests, but specialised medical staff interpret the test results and recommend treatments. They may also investigate the treatment results and recommend other treatments. Nurses are often the staff who issue treatments. Test results and treatment information is both stored with the bed of each in-patient as well as entered into the Cancer Research Share-Net.

*\*Palliative care assists patients who have a life limiting illness to be as symptom free as possible.*



At the La Trobe School of Cancer Medicine, research staff and students have access to raw test results and treatment results. It is important that these results come with details about the people who were tested such as:

* smoker/non-smoker
* other illnesses
* family history
* diet and exercise

The raw data is processed and conclusions made based on the results of various treatments. For example if the data returns a finding that patients with a history of heart disease in the family tend not to respond well to drug “x” then researchers can write a paper for an internationally recognised journal to publish this finding – which in turn may encourage further research around the world into drug “x” and patients with a history of heart disease. It will also influence medical professionals in the choice of drugs they prescribe for their patients.

The new Cancer Research Share-Net will make available all test and treatment data along with other health details about each patient. This will be a great data-mining research tool for cancer researchers.

