

The Thought Leadership Forum 2016

It was exciting to learn that the development of 'safety and quality registers' will be a focus for the Medical Research Future Fund. At last, support for collecting data that can be used to support evidence based medicine. However, as usual, the devil is in the detail. We have been informed that the Minister, The Hon Susan Ley, has requested that COAG develop a national approach to the use of and purpose of medical registries. The idea being that there are many already in existence but that they lack a common purpose.

If we focus on 'safety and quality' data, then we will be collecting data about what currently happens whenever there is a medical intervention. These are initiated by patients when they engage with the medical system. Of course, we want to ensure that each time this happens patients are dealt with safely and receive the best possible interventions. The data we don't collect will include:

- Information about people who don't use the health system, whether they are well (what do they do right?) or choose to use alternate health solutions, or simply suffer in silence.
- Data collected about interventions only. We believe that people with spinal cord injuries experience a significant range of medical challenges that would never be recorded on this type of register. We believe that a 'whole of life' register will provide critically important information about what is really happening and give insights into how to improve their lives.
- By recording data about what has happened in the health system, we will not collect data that helps us predict the likelihood of future health interventions. It will simply tell us what has happened in the past. To properly understand future needs, we have to collect data that points to the future.

It seems that investment in medical registries will be delayed by at least 12 months while government considers this national approach to registries.

One thing that became clear is that pools of data about people with spinal cord injury exist around the country. They range from manually recorded information in isolated hospitals to the national acute data base that is hamstrung by lack of funding and bound up in miles of governance red tape making it almost impossible to function. This data is virtually useless for research purposes. It is collected for all sorts of reasons other than research such as to facilitate payments, regulate or ration services and prevent over servicing. Consequently, every time a research project is contemplated, the data and the data system must be collected or created from primary sources to inform the project. This adds considerably to the cost of every research project.

The registry that we seek to establish will be designed to collect all sorts of information to support research as well as commercially valuable information that can be traded to fund the ongoing administration of the registry.