

COCHRANE RENAL GROUP TENTH ANNIVERSARY IN SYDNEY

Thank you for inviting me and making it possible for me to be here.

The Cochrane Collaboration, and in this instance, the Renal Cochrane Group, have changed the ways that many renal treatments are conceived and undertaken and our understanding of renal diseases has changed and grown as a direct consequence of the research and reviews undertaken by the Renal Cochrane Group. Whilst metadata research and carefully refereed reviews might seem arcane, the outcomes for patients have been practical and utilitarian. The change in cranberry consumption can be directly linked to the Renal Cochrane Group!

I will leave it to others to document these important outcomes because what I want to briefly focus on are the processes that the Cochrane Collaboration as a whole, as well as this Renal entity, have developed and employ because they provide, in my opinion, models for research, treatment, program and policy development and consumer engagement that should inform future medical developments. Obviously, the greatest contribution the Cochrane has made so far is to promote evidence-based medicine and demonstrate ways of 'creating' evidence, evaluating it and acting on it. Evidence-based medicine is now institutionalized into the rhetoric, and occasionally action, of health departments around Australia and the world and has spilled over into other areas like education and social welfare.

My perspective is that of 'the consumer' and I would like to start by expressing my admiration for the work of the Cochrane Renal Group and its staff and its Advisory Board. I was one of two consumer representatives on the Advisory Board for about five years at the start of this century, and have participated in reviews for the Renal and Skin Groups.

I dislike the term 'consumer' with its input/output, supply/demand connotations and overtones of passivity mixed with rapaciousness but it is a commonly used term, it is part of the lexicon of the Cochrane Collaboration and I'll continue to use it. Like most 'medical consumers', my participation in the medical system and my subsequent activism emerged from a diseased background – renal failure, dialysis, transplants. It is important from a consumer perspective that consumers are seen to have more than their medical experience to offer the partnership with the medical world in which they are forced to enact their part as participants or patients (I am not too fond of that latter word either with its overtones of 'quiescent suffering').

I have participated in many medical forums as a consumer and in many, consumers are invited as "the right thing to do", or because it is a requirement, often seen by professionals on committees or working groups as an impost. Such groups do not really know how to make good use of the consumer experience and advice. Consumers in such groups feel patronized: an adornment rather than a useful appendage. Many consumers use such relationships to vent their anger and frustration at what they see as an inhospitable medical world.

The great thing about the Cochrane Collaboration as a whole, and the Renal Group in particular, is that its structure has roles and responsibilities for consumers that are clearly described and it is very clear about the purposes for including consumers as participants and outcomes that can be expected from consumer participation. Consumer engagement in the evaluation and reviewing processes is different from, and additional to, the work of medical clinicians, researchers and writers. Consumer input is seen to ground the research in experience, and value-adds:

The aim of any medical care is to benefit patients. Ultimately, the best person to judge whether any healthcare intervention has been beneficial is the patient. (from the Cochrane Collaboration website <http://consumers.cochrane.org/cochrane-groups>)

It is a partnership that makes productive use of the specialized experience of the consumer as a particular ingredient in the mix, not as a patronizing feel-good thing to do. The Cochrane Collaboration believes that its information products based on evidence in relation to practice, cannot be achieved

without this. Consumer engagement in the reviewing process also ensures that products are achieved that consumers can understand and act on.

As an educator I am aware of the changes required in curriculum and teaching methodologies as the social learning capital increases. We have the most educated parent cohort currently that we have ever had. Not only do educators need to be aware of this group's changed expectations of learning for their children, but we also need to take account of, and use, this enhanced capacity to access knowledge and learning in the home. Changes in the ways that information can be accessed through technologies are also significant in my industry. The medical world is coming to understand that patients and their families are more educated, have a greater capacity to analyze information and have uninhibited access to information and a significant capacity to reach conclusions, make judgments and create knowledge for themselves .

The Cochrane Groups understand this and produce information, based on reviews and analysis that engage patients as sentient beings. These analyses are published on-line and in newsletters. They put information about evidence based medicine into the hands of patients as well as doctors: they help put the 'informed' into 'informed consent'. Cochrane assists in creating partnerships among doctors, patients and researchers through the creation of knowledge. The Cochrane Collaboration has been significant in creating this useful, defined partnership role for consumers and it has provided a model for other groups that engage with consumers.

Governments are also looking for such partnerships as part of new forms of governance. Terry Moran the head of the Prime Minister's Department has shifted Health governance directly to the Council of Australian Governments (COAG) in a further step removed from traditional health policy decision-makers:

I think the current COAG process has now reached a point where it is apparent that the total body of reform possibilities is broader and more substantial than all of the national competition policy reforms of the 1990s.

We need a bold approach to reform. And to achieve such reform, we need a new way of governing—in particular, increased cooperation between federal, state and local governments, businesses and community organisations.

A renewed belief in the possibility of reform was apparent at the 3 July 2008 COAG meeting. Leaders reaffirmed their commitment to the goals of the COAG reform agenda to address the challenges of:

- boosting productivity*
- increasing workforce participation and mobility*
- delivering better services for the community.*

Reforms in these areas will in turn contribute to achieving broader goals of social inclusion, closing the gap on Indigenous disadvantage and environmental sustainability. An overriding principle is that the key to building a strong economy is long-term productivity growth and participation in the workforce. (Moran, Terry, Splicing the perspectives of the Commonwealth and states into a workable federation, keynote address at the ANZSOG Annual Conference on 12 September 2008, reprinted as Chapter4 in *Critical Reflections on Australian Public Policy*, ANU Press 2009)

I trust that the Australian government, and governments elsewhere, will extend their recognition that the Cochrane Collaboration, through its focus on evidence based medicine and its structures that include consumers as partners, has an important role in creating new medical paradigms for developing policies and programs in healthcare.

Not only has the Cochrane Collaboration played an important role in making consumers useful, it has demonstrated a further capacity link consumers as well as doctors and medical researchers across the world. It is both an international organization and a global one: 'international' in the sense that it connects 'nations' and their nationals and shapes healthcare delivery in particular countries in particular ways; 'global' in the sense that it connects individuals as well as groups across boundaries and borders, and recognizes and assists patients and doctors to recognize the 'globality' of their diseases and treatments. Moreover, and necessarily, it relies on changing global communication systems and technologies to do so in ways that provide models for others. It has divided up responsibilities in a useful management model, eg the Cochrane Renal Group is located in Australia for resource, logistical and expertise reasons, but the approach and connectivity is always global.

Patients as consumers are connected in a global partnership. The value of this as a model and its importance of taking patients beyond the narrow worlds of their clinics and their waiting rooms cannot be over-estimated. Cochrane has a global framework at the same time the Australian government is struggling to create a national one.

The Cochrane Collaboration is no doubt considering the benefits and risks of cloud computing 'a billowing virtual infrastructure for services – and savings'(CoSN EdTechNext Winter 2009/10 Cloud Computing). As more patients use public clouds in their day-to-day lives, they will expect that their health services will be provided without either obvious gateways or impermeable membranes. From an individual perspective the service, product or infrastructure should be available as and when they need it via the media or devices of their choice. Collective cloud computing might enable more efficient and cost effective services, especially where support and maintenance must be provided to small, geographically distributed sites, often in locations, including homes, without technical expertise. Public cloud computing opportunities raise questions about the efficacy of jurisdictional boundaries in health service provision because they become unnecessary. The Cochrane Collaboration with its global frameworks is well placed to comprehend and act on these information and communication technological shifts.

I have lost the purpose of this commentary and have finished up in the clouds. I apologize. Happy anniversary to the Cochrane Renal Group: it's a great achievement given the vagaries of funding and shifting priorities. Your ten years as a productive and highly valued group is a testament to the drive of the individuals involved and to their dedication and professionalism. And **that** is what we consumers are celebrating.

Jim DELLIT

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