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**Regarding Medical Cannabis/ State of Victoria/ Chronic Pain/ A Registry**

**If the VLRC report makes a recommendation that certain patients with chronic pain be granted access to medical cannabis, in defined groups and exceptional circumstances, I urge consideration for evaluation of those patients and the outcomes of the treatment undertaken include the compulsory use/ enrolment into a Clinical Registry.**

A clinical registry can collect real world data, of an observational and self-report nature, for the purpose of safety, quality of care and evaluation of effectiveness. A registry is defined as “an organisational system that uses observational methods to collect uniform data, clinical and other, to evaluate specific outcomes for a population defined by a particular disease, condition or exposure that serves a predetermined scientific and clinical scientific or policy purpose.” It is distinctly different to a prospective clinical trial.

In the field of chronic pain good guidance has been achieved through international consensus of what is useful to measure outcomes or results of intervention. Please refer to IMMPACT guidelines (Dworkin R et al. Pain 2005). http://www.immpact.org/static/publications/Dworkin

In Australia we have recently established a chronic pain outcome registry: called the electronic Persistent Pain Outcomes Collaboration (ePPOC) at the Australian Health Services Research Centre at the University of Wollongong. <http://www.ahsri.uow.edu.au/eppoc>

The initial and follow up questionnaires are available via this link and would constitute a suitable set of questionnaires for a medical cannabis chronic pain treatment evaluation. The established registry could be used for this group (with funds allocated to do so). Details collected include: Patient demographic information, Work status, pain history onset aetiology , location, health care utilisation, medication use, Brief Pain Inventory (BPI) , Depression, Anxiety, Stress Scale 21 (DASS) Patient Self Efficacy Questionnaire(PSEQ), Patient Catastrophizing Scale(PCS) (refs available). Statistical results are available.

To these measures we would specifically add-

* if withdrawal from cannabis use: reason, adverse effects
* details of specific medical cannabis form and dose used.

The use of a Registry would allow useful evaluation, something that appears lacking from international programmes that have allowed medical cannabis usage.

A Registry would not obviate the need for proper clinical trials to evaluate effectiveness and safety.

The Faculty of Pain Medicine has strongly supported ePPOC establishment and would support my recommendation as above. Note: I am a member of Scientific and Clinical Advisory Board of ePPOC, and formerly of its National Reference Group)

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