STANDING COMMITTEE ON HEALTH, AGEING, COMMUNITY AND SOCIAL SERVICES – INQUIRY INTO THE EXPOSURE DRAFT OF THE DRUGS OF DEPENDENCE (CANNABIS USE FOR MEDICAL PURPOSES) AMENDMENT BILL 2014 AND RELATED DISCUSSION PAPER

My background

I retired due to invalidity at the age of 54. Prior to retirement, I was an IT project manager and a certified Project Management Professional (PMP[®]). Before I changed my career to work in the IT industry, I was a microbiologist and food technologist.

I am diagnosed with several medical conditions but the main disease impacting on my daily quality of life is Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome. (In USA, CFS has just been reclassified as a disease and renamed "systemic exertion intolerance disease" or SEID for short, by the prestigious US Institute of Medicine: http://www.iom.edu/Reports/2015/ME-CFS.aspx; accessed 13 February 2015).

Currently there is no cure for SEID, or treatment that works for me.

Prior to my health issues, I was very physically active. I was an avid cross-country skier, backpacker and all-round outdoors enthusiast.

Due to my health issues, I am mostly housebound and bedbound. I cannot carry-out routine domestic duties so I am reliant upon my spouse whom retired early to be my carer. So instead of enjoying our retirement, we are challenged by my many health issues.

I rarely venture out of the house and when I go window-shopping for about 1-2 hours, for example, I will be utterly exhausted for up to 3 days.

I have lost the friendship of many people whom cannot comprehend my health issues and ME/SEID in particular. Ditto my family members. I am isolated socially.

I am still grieving over my invalidity, and loss of amenities and lifestyle.

My use of marijuana for self medication and related impacts

There is no pharmaceutical medicine available and specifically targeted for SEID.

Until last year, marijuana was not on my radar. But at the age of 55, I started using marijuana to assist in the management of my many medical symptoms. I'm now 56.

I regard myself as a moral, religious and law abiding person – except that I am using marijuana medicinally. So I guess Australian society no longer considers me to be a law abiding citizen under current legislation.

I feel quite stigmatised by uninformed people's perception of my use of medical marijuana.

I am *not* a recreational marijuana user.

I use marijuana for the management of chronic pain and nausea, to assist me to sleep and for managing other medical symptoms.

As it is illegal for my treating GP to advise me re marijuana or to prescribe it for my conditions, I have been on a steep self-learning curve to get across the use and utility of marijuana medicinally. For other people, they may not be in a position or be equipped to educate themselves about the use of marijuana medicinally. Thus people with medical conditions who could benefit from using marijuana medicinally should have access to a medical system that supports their use of marijuana.

At aged 56, I am worried that police will break down my front door and confiscate my medicinal marijuana, and incarcerate me for possession of an illegal substance and my spouse whom buys the medicine for me (as I am mostly house and bedbound).

As retirees on limited incomes, the cost of purchasing marijuana (in some back alleys) is really impacting on us financially. This is ridiculous when one considers that marijuana can be grown at minimal costs in one's backyard and relatively easily. However, ACT's decriminalised quantities and the allowance of up to two plants are inadequate for my medical needs.

Double blind studies – not necessary

As an ex-scientist/microbiologist, I am appalled and frustrated by some members of the Australian medical/health professions whom demand that double-blind studies must be carried-out to demonstrate marijuana's safety, utility and efficacy as a medicine.

These doctors and "professionals" chose to ignore the existence of overseas studies that overwhelmingly supports the medical use of marijuana – e.g. refer ACT Green's discussion paper.

Otherwise, they demonstrate their lack of understanding of double blind studies, and/or they have motives that are inconsistent with their public persona of acting for the public good – frankly, some of these people should stay within their areas of expertise and stop messing around with other people's lives and wellbeing.

It has been estimated that thousands of Australians are already taking marijuana medicinally (source unreferenced), and of course there are people overseas using it medicinally – I'm not even counting those using it recreationally. Therefore, the sample size for *in vivo* testing is already hugely more than enough to demonstrate marijuana's relative safety and its risk management.

The world's population has already been in Phase III clinical trial and beyond, for decades and generations!

As for medicinal marijuana's utility and efficacy, I think the consumers of medical marijuana have already determined that for themselves – *people like me are demonstrating "civil disobedience" in using marijuana medicinally because it works for us.*

We can't wait for the uninformed or those with questionable motives to catch up.

Why spend much more money, time and effort to conduct trials that are unnecessary? Some patients do not have years, months or even weeks to wait for redundant trials.

On this issue, I am mindful and support the views recently expressed by University of Melbourne's Professor David Penington and a former National Health and Medical Research Council member, in an article published in the *Medical Journal of Australia* in which he wrote:

"The clinical trial proposed (in NSW), if successful, presumes that cannabis would then be approved and regulated as a pharmaceutical substance.

Cannabis can never be a pharmaceutical agent in the usual sense for medical prescription, as it contains a variety of components of variable potency and actions, depending on its origin, preparation and route of administration.

Consequently, cannabis has variable effects in individuals. It will not be possible to determine universally safe dosage of cannabis for individuals based on a clinical trial."

(http://www.smh.com.au/act-news/expert-argues-medical-marijuana-trials-of-little-use-20150201-130snw.html; accessed 14/2/2015)

Comments on the draft legislation

I now turn to the draft legislation *DRUGS OF DEPENDENCE (CANNABIS USE FOR MEDICAL PURPOSES) AMENDMENT BILL 2014* and related discussion paper.

In general, the legislation is a move in the right direction and a long time in coming. The proponents and supporters of this legislation should be applauded.

Grouping patients/conditions into Categories 1-3

I understand that it may be helpful and facilitate administration of the legislation if patients are slotted into categories of:

- Category 1 for terminal cases.
- Category 2 for declared prescribed medical conditions
- Category 3 to allow for consideration, approval of other non-prescribed conditions (declared under Categories 1 and 2)

From my understanding and interpretation of the draft legislation, I may be slotted into Category 3.

But I think it would be against the spirit of the legislation to construe or to construct a hierarchical system of categories – that Category 1 patients are more deserving or have higher priority than Category 2 patients; ditto for Category 2 over Category 3 patients.

I have had over 30 years to develop my many health conditions/diseases which were either ignored or misdiagnosed by various doctors until too late and I am now an invalid. Am I to be classed or considered to be less deserving somehow if I am slotted into Category 3?

Role of the Chief Health Officer (CHO)

I understand that it may be administratively efficient if the CHO makes a determination – that there is only one-single point of decision making over issuing permits etc. But I wonder if this places too much arbitrary power in the hands of one person.

So if the CHO's determination is to refuse a permit and then it is appealed to a review board or officials, I recommend that an advocate-for-patients be a compulsory element of the review entity or process.

While I have more ideas in my head, regrettably I am too fatigued and not able to comment further at this time.

Again thank you for the opportunity to make a submission and comment on this humane initiative.