Queensland Parliament's Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee

6th January 2019

Personal submission from:

Lanai Carter

Re: Health and Other Legislation Amendment Bill 2018

Dear Committee,

- I am specifically addressing the section of the bill relating to repeal of the *Public Health (Medicinal Cannabis) Act 2016*, and the proposal to make "consequential amendments to the *Health Act 1937*, to significantly streamline the regulatory framework for prescribing medicinal cannabis in Queensland"

I am commenting based on our experience with my sons' medical cannabis applications.

My son was the first patient approved in Qld for medical cannabis and the first patient approved for schedule 9 botanical cannabis in Australia.

I support the repeal of the Public Health (Medicinal Cannabis) Act 2016 for the following reasons:

- The existing legislation has caused extreme hardship and harm to patients and their families in Qld.

- There has been a duplication in process between TGA and Qld Health medical cannabis application assessment.

- The parliament failed to act based on the clear evidence provided to them of the duplication in process between state and federal government departments from the parliamentary committee hearings in 2016. (Report No. 26, 55th Parliament – Public Health (Medicinal Cannabis) Bill 2016)

- The parliamentary committee were provided with firsthand accounts of the duplication that was already occurring during the processing of my son's application for medical cannabis.

  https://www.parliament.qld.gov.au/documents/committees/HCDSDFVPC/2016/PH-MedicinalCannibas-Bill2016/submissions/067.pdf

  This evidence highlighted the duplication of processes between the state and federal government application processes and the impacts on patients. This duplication was

previously denied in parliament by Qld Health representatives when they were questioned by the committee. However, in the explanatory notes for the current proposed bill it seems that there is finally an acknowledgment of a duplication of process.

- Qld Health has acted in a manner which has been irresponsible and has negatively and significantly impacted patients and their families including our family and has caused unnecessary stress and harm for sick patients in Qld.

  In the case of applications being assessed for my son these problems have included:

  - Breaches of privacy by Qld Health Staff
  - Qld Health Staff trawling and collecting data from a personal Facebook page relating to patient
  - Duplication of assessment between TGA and Qld Health
  - Non-disclosure by a clinical review panel member of a conflict of interest
  - Requesting medical information from doctors and specialists which had already been provided to Qld Health
  - Qld Health staff member attempting to intimidate doctor who was prescribing medical cannabis
  - Qld Health imposing unreasonable conditions despite requests for common sense to be used (the requirement to purchase an expensive medical device from Germany when a near identical device from same manufacturer was owned by patient already)
  - Changing prescription frequency from 6 monthly to monthly scripts causing further appointments and hardship for patient/carer. (This was in addition to quarterly reporting appointments with doctor plus all the appointments with doctors and specialists required to work through the application process).
  - It appears there were attempts to intervene or interfere in TGA processes relating to my son's application
  - Changes were made to a product being approved by Qld Health when another product had become out of stock without prior consultation with my son's doctor
  - Discussions between Qld Health staff and medical supplier (about the patient's application) without the consent of the doctor and patient.
  - Discussions between Qld Health staff and medical supplier about dosages for patient without consultation with doctor and consent of patient.

- Queensland Legislation does not currently allow a provision for Category A where a doctor can prescribe without the need for state application process. TGA only requires a notification from the doctor if the patient meets the definition under Category A (https://www.tga.gov.au/form/special-access-scheme)

Prohibitive costs and a lack of affordable options

In addition to the above issues the state and/or federal government has not provided any affordable access options for most Queensland patients to cannabis medicines.

In many other countries/states across the globe there are a range of laws which allow patients to have affordable access options and to be able to change or access products efficiently and as required for their medical condition and symptoms.

Costs under the current system are completely prohibitive for patients like my son who have been recommended and successfully treated with medical cannabis in the past.

The retail cost of medical cannabis for my son would be in excess of $48,000 per year depending on supplier used. Considering the annual average income of Australians is $52,988 this would mean that medicine costs alone would exceed an annual income for most people.
http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/6333.0Main+Features1August%202017?OpenDocument

Local supply challenges

There have been significant delays in the issuing of licences and permits by the Office of Drug Control for Australian companies, this has in turn also impacted supply, cost, accessibility for patients in Qld and federally.

The current situation of overregulation, unaffordability, delays and other issues has left many patients abandoned with no possibility to afford access or to access suitable products through the current system.

Patients who may require specific medicines/potency/cannabinoid ratios/specific strains for treatment of their conditions have been put in a position where there is no suitable supply here from licenced producers.

Import delay impacts

Recently Health Canada reported that it is taking up to 130 days to issue export permits for cannabis oil and up to 30 days to issue export permits for cannabis flower, this combined with shipping, import/export delays and application processing times has left patients in a vulnerable situation with inaccessibility to specific products and delays of up to 5 months or more to access specific products which may be coming from Canada , this has been part of the cause of gaps in supply in my sons case in the past.

With the local medical cannabis supply currently heavily reliant on imports until local industry has been established there has been no foresight or proper management of this situation to ensure adequate, efficient or affordable access to medicines.

Unsuitable system for a complex herbal plant

Because of the diversity of this plant, it should never have been limited to a pharmaceutical regulation model exclusively in Australia.

I agree with and support a model like the previously proposed Regulator of Medical Cannabis 2014. I believe a suitable model should also remove regulation of all herbal medicines from the TGA and allow them to be managed by a regulator which can truly respect and accommodate the diversity of herbal medicines and the way they are prescribed and used globally.

Although this model would be separate from the TGA it should allow patients to be able to use prescribed herbal medicines (including cannabis medicines) in a health care setting or locations where medicines are permitted.

Practitioners such as Naturopaths who have more in-depth knowledge and expertise of herbal medicines should be able to legally recommend this medicine also.

This plant had been used safely, wisely in communities globally for millennia and unfortunately became a victim of corporate and racist prohibition.

This a complex plant with many different cannabinoids and terpenes which can change vastly from one plant or strain to the next.

In my sons case even the smallest difference between strains, potency or extraction methods for example can make a difference between whether a product is suitable or effective for his condition and/or symptoms.

Once safety has been established types of evidence base that is accepted within scientific circles are for example N=1 studies and longitudinal observational studies to further research and data collection. This will still enable evidence-based guidelines to be given to health professionals.

Lack of flexibility and efficiency to adjust medicine dose, type, supplier under current system

As with all herbal medicine's treatment must be individualised or tailored to the patient and condition on a personal basis.

The current system does not support the best outcomes for patients because its difficult for doctors to amend or change dose, products or suppliers without copious amounts of application process and prescription changes.

My son has previously had access to specific strains from licenced producer which stopped focal seizures after they had initiated by vaporising but this product became unavailable (out of stock) and was not able to be imported, leaving him without the best product options for his condition. You can imagine the frustration of a doctor having to process a

new application every time a new product was to be trialled to find a replacement product that would be as effective as one previously.

If a doctor had to change medical cannabis product for a Category B patient, they would need to send new applications to Qld Health and TGA, await approval and then (if product coming in from overseas) a delay whilst waiting for import. Months could have passed before a patient could trial a new medicine and see if it was effective.

An advantage of an authorisation model such as Canada or some states of the USA allows changes to dose, strains, products or suppliers efficiently, often within the same day or within 48 hours.

It is my hope that any changes made can prioritise the health and wellbeing of patients first and foremost.