Health Consumers Queensland submission

Queensland Parliament

Health, Communities, Disability Services and Family Violence Prevention Committee

Inquiry into the Health and Other Legislation Amendment Bill 2018

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About us

Health Consumers Queensland is the peak organisation representing the interests of health consumers and carers in the state. Health Consumers Queensland is a not-for-profit organisation and a registered health promotion charity and we believe in improving health outcomes for people in Queensland.

Consumers are people who use, or are potential users, of health services including their family and carers. Consumers may participate as individuals, groups, organizations of consumers, consumer representatives or communities.

Our priority focus is on consumer engagement that influences and leads improvements and delivers better health outcomes for all Queenslanders. We achieve this through our Queensland-wide health consumer network, tailored training and skills development programs, and maximising opportunities for consumer representation at all levels of the health system.

Consumer engagement is when health consumers actively participate in their own healthcare and in health policy, planning, service delivery and evaluation at service and agency levels.

Introduction

Our organisation welcomes the opportunity to provide both a consumer and carer, and organisational response to this inquiry. Our submission covers four of the proposed amendments due to their impact on health consumers and carers and the community in general:

1. Repeal the *Public Health (Medicinal Cannabis Act 2016)*, and amend the *Health (Drugs and Poisons) Regulation 1996* to further streamline access to medicinal cannabis in Queensland.
2. Amend the *Public Health Act 2005* to:
    a. establish a dust lung disease register,
    b. to require prescribed medical practitioners to notify the chief executive of Queensland Health about cases of notifiable dust lung disease, and to require the chief executive to report on these notifications.
3. Amend the *Transplantation and Anatomy Act 1979* to:
    a. clarify the provisions about research that involve removing tissue from adults and children
    b. remove the requirement that a post-mortem examination of a body conducted in a hospital only be held in the hospital mortuary.
4. Amend the *Births, Deaths and Marriages Act 2003*, the *Coroners Act 2003* and the *Cremations Act 2003* to enable human body parts used for examination or teaching purposes in schools of anatomy to be lawfully cremated without a corresponding death certificate or the approval of an independent doctor.

We have chosen not to comment on ***Amend the Radiation Safety Act 1999*** or ***Amend the Retirement Villages Act 1999.*** We have also not commented on **Amend the Transplantation and Anatomy Act 1979 to ensure pathology laboratories can access tissue-based products that are necessary for diagnostic and quality control purposes**.

We reserve making a recommendation on ***Amend the Transplantation and Anatomy Act 1979* to clarify the provisions about research that involve removing tissue from adults and children** and recommend that there be further consultation with families (see that section of our submission for more detail).

Our submission is focused on these consumer-focused principles of person-centred, integrated health care:

- Accessibility - safe, affordable and high quality services, treatments, preventative care and health promotion activities.
- Respect - healthcare that meets consumers' unique needs, preferences and values
- Choice – a responsive health system which ensures consumer choices in treatment and management options
- Participation - patient involvement in health policy to ensure that they are designed with the patient at the centre[1].

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[1] International Alliance of Patients' Organizations (2006) Declaration on Patient-Centred Healthcare (IAPO: London) https://www.iapo.org.uk/sites/default/files/files/IAPO%20Declaration%20on%20Patient-Centred%20Healthcare%20Poster.pdf

How we consulted

As the Health and Other Legislation Amendment Bill 2018 is of interest to health consumers, their families and the general community we sought to gain consumer feedback and comments on what is a variety of amendments. To do this, we developed a detailed survey that provided a brief of each amendment and asked specific questions. The survey was distributed to the Health Consumers Queensland state-wide consumer and carer database, to specific health NGO's and to relevant community support groups. It was promoted and shared on Facebook and through our eAlerts. Individual contact was also made with specific community groups and organisations to gain their support in seeking feedback from their members.

Respondents could complete the full survey or focus on the amendments that were relevant to them or their families. The survey was available for a period of 7 days and resulted in a total of **73** responses.

Along with the consumer and carer survey results and comments we have incorporated our organisational knowledge and the voice of our staff and Board members into this submission.

1. **Repeal the *Public Health (Medicinal Cannabis Act 2016)*, and amend the *Health (Drugs and Poisons) Regulation 1996* to further streamline access to medicinal cannabis in Queensland.**

Health Consumers Queensland supports the amendment from an organisational perspective.

Our approach to this issue has always been informed, driven by and supportive of families having timely, equitable and affordable access to safe and effective medicinal cannabis products (refer to our submission to the Inquiry into Public Health (Medicinal Cannabis) Bill 2016 (dated 11 July 2016) and Inquiry into Public Health (Medicinal Cannabis Affordability) Amendment Bill 2017 dated 27 April 2017).

Due to this approach, we recommend that 'specialist general practitioner' be amended to include General Practitioners (RACGP) to enable more consumers and families timely and affordable access to Medicinal Cannabis.

Through the survey we took the opportunity to see if consumers, carers and family members also agreed with the amendment and to learn what benefits they would gain for themselves or their family. The survey outcomes provide a strong positive response.

Question 1: Do with you agree removing the barriers for patients and doctors seeking access to medicinal cannabis treatment?

YES	**86.11%**
NO	0.00%
Not Sure	2.78%

11.11% of respondents provided **Comments**. We have captured the main themes from these comments below:

While the existing system was designed to ensure patient safety and allay concerns of the broader community as to the use of marijuana, the restrictive nature of the process has caused more harm and distress to patients and their families and carers/support givers. The recommended amendments are long overdue and enthusiastically welcomed.

I would like more evidence and research into the ongoing results of people using medicinal cannabis especially any improvement in condition in regard to initial diagnosis.

It should be treated like other controlled medicine. GP's know what is required and qualified to advise the patient about this and any other drugs.

I believe it needs regulating and accountability. Where it is research based to provide best care and doctors themselves are knowledgeable and disciplined in its use, including following up on patients e.g. addictive side effects.

Question 2: What benefits do you believe you or your family member will gain from this amendment?

There was a significant response to this question and we have incorporated a number that reflect the views both as positive and not so positive responses.

Supportive

We have had patients seeking access to pain management and therapy options and their treating doctor has recommended utilising medicinal cannabis - yet the delays in access and administrative requirements have resulted in significant distress/confusion and in some cases, patients enduring the pain rather than bothering with the legal process to gain access. Further, many patients have elected to access marijuana through "other channels" given their desperation and frustration in seeking access to medicinal cannabis pain therapy through legal avenues. The proposed changes will ensure patient safety and remove the risk of patient exploitation. Additionally, the changes will provide patients with an efficient and reliable means of pain therapy that does not make them or their families face legal ramifications for breaking the law and also removes the societal stigma surrounding their treatment choice.

I am currently receiving medical cannabis [since 10-10-18] and it has been of great benefit to my chronic pain condition. The Federal Health Minister [Greg Hunt] should consider changing his black and white view that Cannabis "is a gateway drug to heroin" [unquote], as the real gateway drug is alcohol!

Our family is very familiar with the painful effects of cancer following the death of my grandmother and father with various forms of the disease. Cancer is hereditary in our family and I have seen first-hand loved ones succumb to the immense physical pain. Having access to medicinal cannabis has the potential to alleviate a portion of this pain, if only temporarily, for future generations of our family including myself.

My daughter has refractory epilepsy due to a brain malformation and we have been waiting many years to try medicinal cannabis.

Another option available to treat a myriad of health problems. I believe in the legal right for palliative and untreatable patients who wish to try anything to alleviate their condition.

Use for terminally ill child with cancer, without waiting 4 months.

Increase appetite in my child who is currently undergoing chemotherapy. As well as assisting with her pain.
That she will be pain free and able to get around better and no being able to do anything at all not moving from her bed and home some days is not living.

Will prevent us from being treated as criminals and having to seek unverified or unsafe products from out of state.

I live with severe chronic mental health issues relating to Post Traumatic Stress Disorder. Easier access to medicinal cannabis will eliminate some addictive pharmaceuticals that currently allow me *to gain some sleep. There is much evidence regarding the use of edibles and their positive impact on sleep for people with my condition. This is a very compassionate response from Government.*

Choice, options for palliative and medical care. Optional pain relievers or in addition to current pain medication, Disability clients and clients with chronic rare disabilities.

Not Supportive

Personally see no benefit. Possible damage leading to over use and transfer to Cannabis use.

I am also concerned that people who choose to regularly use cannabis without medical reason have asked me: "What would I need to look like to get cannabis prescribed?"

2a Amend the Public Health Act 2005 to establish the Notifiable Dust Lung Disease register and require prescribed medical practitioners to notify the chief executive of Queensland Health about cases of notifiable dust lung disease, and to require the chief executive to report on these notifications.

Health Consumers Queensland supports the amendment and establishment of the **Notifiable Dust Lung Register**. However, we would like the register to also acknowledge and support not just paid workforce but others who are impacted by being in the environment (neighbours to building sites for example).

We understand the purpose of the register and the need for privacy for those listed on the register and that it is not a public register. However, we used this as an opportunity to learn from consumers if there was any aspect of the register they would like to see made public and if so, how would they want that information provided. We also asked what they would consider as the risks and benefits of being on the register and who would they want to tell them about the existence of the register. In this way, if the amendment is passed, it would provide advice to Queensland Health on what consumers consider important to them in relation to the establishment of the register and therefore inform how its purpose should be communicated to the community.

Question 1: This is not a public register. Is there any aspect of the register you would like to see made public and if so, how often and in what way would you want that information provided?

It would be useful to know if there is a cluster of these conditions in a particular location, perhaps due to environmental or polluting conditions that pertain to that location.

The public has a right to understand and be educated about associated risks and their level of the risk involved in being employed in any workplace. Employers may not always be so forthcoming with this information if it has potential to impact employment. The annual report provided to the Minister should be made available to the public at the very least.

The aim must be to prevent or limit the possibility of exposure to causes of such diseases. This would seem difficult if there is no public disclosure. However, publication need not involve names but numbers, details, causes and locations.

It should have a victim de-identified summary available online showing what is happening in which companies and locations so the public can make an informed choice about working in those companies or purchasing their products.

The privacy of the patient (and their family) is always of paramount importance and this needs to be weighed against the benefit to the community of sharing information. Information that is de-identified could provide community members with insight into how many people are affected and where/how exposed. This could provide an alert to people who may have had unknowing exposure and may benefit from undergoing investigations into their own susceptibility. Perhaps it could also assist to have information as to the number of fatalities to enable the community to understand the full impact of dust diseases not just on the individual diagnosed, but their extended family, friends and community.

Question 2: As a family member or someone working in an occupation that involves exposure to inorganic dust, what information do you want to know about this register? If so, what are the risks and benefits of being on the register for you or your family member?

How confidential is his information? Will he be fully informed of the purpose of this data collection and how it will be used in the short and long-term?

Does being on the register ensure a patient will be given treatment and other assistance in a timely manner?

The benefit of the register, could assist future generations regarding harmful exposure, based on statistics, and awareness of this occurring in community.

Ease of access for the public to the register, where to access immediate/time critical treatment. Zero cost to the public or person/s impacted.

My husband used to work inside the hull of a bulk carrier that carried cement dust. I want to know it hasn't affected him at all or if it has.

Being on the register means information about these illnesses can be collected more accurately and perhaps provide more peer support for those affected.

Question 3: Who do you want to talk to about being listed on the register?

- Specialist or GP
- A health professional, a workplace health and safety officer.
- Workplace Health and Safety.

Other Comments:

Set up the register and make reporting by health professionals mandatory.

This is important as these diseases are on the increase.

Once a risk is identified everyone is obliged to speak up.

Doctors who inadvertently out of ignorance do not report should be handled gracefully.

2b Amend the Public Health Act 2005 to enable the chief executive of Queensland Health to require a person responsible for causing a pollution event to publish a pollution notice to inform the public of potential risks to public health.

Health Consumers Queensland supports the amendment and acknowledges Queensland Health for taking this direction.

As the community is the most likely to be impacted the most by pollution events we were keen to learn not only if they agreed with the amendment, but also how they would want to be informed about an event and how quickly.

Question 1: Do you agree the amendment is a positive move in ensuring the health of Queenslanders during major pollution and contamination events?

YES	**87.14%**
NO	0.00%
Not Sure	7.14%

5.71% provided Other Comments:
Any and all persons/entities should be obligated under law to notify the public of pollutants and possible risks and health hazards to the public. Immediate safety plans should be implemented by those persons/entities, and costs associated with reparations be enforced promptly.

If I understand; the improvement is a second notification by those that caused the pollution or they get a fine? The power for notice is already within the Act. I do agree that more information in the public domain can only assist

Yes however does it go far enough i.e. pandemic type illnesses even things like food poisoning?

Question 2: How would you want to learn about a pollution event that may pose a risk to your health or the health of your family?

The overall response was that information should be provided:

- Via text in the same way as a natural disaster
- All forms of media including social media
- Queensland Health website and Facebook
- Queensland Government website

This should be considered in context - if there is a direct and immediate threat then the notification needs to be as efficient and clear as possible. For example, telephone message (sms), Facebook post, radio announcement and television broadcast. If there was an imminent but not immediately threatening threat then it would be good to have a way of offering written information of the threat so the affected community could make an informed decision as to the risk to their personal circumstances. It is important not to create hysteria where the risk is less immediate and it is also prudent to give proper information to avoid confusion and misinformation.

There could be an app. Or linked to a current app like the BOM (weather app)

Information should cover what the pollutant is, its harmful nature, any and all side effects, and how to avoid it. If damages are incurred, immediate safety plans should be implemented by those persons/entities, and costs associated with reparations be enforced promptly

Question 2: How quickly would you want to hear that information and the steps you need to take?

Overwhelmingly the survey response to this question was 'immediately' or 'as soon as possible'. One response suggested that as soon as the appropriate facts were known people need to be informed.

ASAP whatever is appropriate to level of risk. Particularly to those with family members with low immune strength or low respiratory health.

Immediately. Should panic ensue then all the better as many industries in my region are seemingly less concerned than they should be regarding their obligation to the community and the environment. Too much goes by unreported.

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Depends on the pollution event, but as quick as possible in relation to the danger element

Other Comments:

I am immune suppressed with less than 40% lung capacity. I want to hear about, and how to protect myself from, anything that can jeopardise my breathing/health immediately.

It is important not only to inform the public as to the risk and threat but also the steps that need to be taken - e.g. evacuation, bottled water, etc. - as well as referral details of any support and services available, including avenues to seek further information and ways to access emotional support in the event of panic, anxiety and anger (depending on the nature of the polluter's actions).

I think members of the public would also like to know what steps could be taken to prevent the event happening again in the future and if criminal charges were laid / fines imposed.

Life at any stage is our common bond and our common wealth and for anybody to not be told of a danger pending or straight away is a crime against our collective humanity because any society is and has always been judged on how it treats its most vulnerable. Without prejudice.

I believe that this amendment will lay public accountability back onto the people responsible for the risk and make room for Queensland Health to continue its focus on improving health outcomes for Queenslanders and a possible action plan in response to the risk.

3a Amend the *Transplantation and Anatomy Act 1979* to clarify the provisions about research that involve removing tissue from adults and children

We wanted to know if parents and consenting adults fully understood the amendment and what it would mean for them or their child. We were particularly interested in hearing the voice of parents and families of paediatric oncology patients in regard to this amendment.

Some of their responses as outlined below suggest changes/clarification to the amendment. This is highlighted in comments from consumers who appear to be strongly concerned about researchers.

We would suggest that additional consultation with families of paediatric oncology patients be undertaken prior to Health Consumers Queensland agreeing to this amendment as it stands. One respondent has asked for this amendment to be debated with community input and we would support this additional consultation.

We asked consumers and carers the following questions:

Question 1: As a parent or consenting adult do you understand the proposed amendments and what they mean for you or your child?

YES	**83.33%**
NO	16.67%

Question 2: Is there any aspect of the amendment that you would like clarified or changed before it is passed?

<u>Supportive</u>

As a parent of an oncology child, it would be helpful to be advised when my child's tissue is being used to benefit research or has been finalised with. A sense of closure similar to how Red Cross advises donors that their blood is being put to good use.

If this was a discussion and permission was shared at the time of consultation with the parents or patients there would be a greater acceptance I am sure. It is my understanding this conversation is held at a time when parents / patient is under duress from the diagnosis when they are not of clear mind. Just a thought.
Consent should always be required if samples of a patient are being kept for research or ANY reason beyond their immediate medical treatment. The patient or guardian should be made aware (in writing) what samples are being taken and for what purposes.

I am concerned that some adults and consenting adult of children would need timely and supportive advocacy. Documentation of both consent and collection must be clarified and transparent.

Add with consenting adult or guardian (if not existing)

As long as the amendments involve adults AND children.

Being sure that informed consent is strictly part of the process. Parents/families should also be advised following any collection of what has occurred

Ensuring that there are regulations in place that will protect any adult and child from any manipulation and malpractice.

The clause that the approved research is for the benefit of the child - in some cases it may not help the particular child, but may improve medical knowledge. I see no objection to this if there is ineligible risk, and minimal discomfort.

Definition of 'child' needs to be modernized.

Definition of approved research.

Not Supportive

We were only advised by respected relatives that we have control of our child's tissue. We then advised that no research be conducted by tissue bank. And now with hindsight a crucial decision. With very minimal cancer tissue collected initially, the remaining piece of tissue is becoming vital and potentially life-saving as research progresses. Researchers have no right to patient's tissue who have a life threatening illness that in the future could be life-saving. Research is moving quickly, and this is all a terminally ill patient has to control their future.

Having a child now with terminal/relapse cancer, there is only one area of control in any life threatening journey, and that is that your child's tissue is theirs.

The explanation needs to clearly state what the current act is, the changes being made and the final wording of the new act. I find the explanation above very hard to follow.

Paragraph two (the removal of tissue occurs during a procedure etc.) should only be consent of the parent/guardian.

To ensure that parental consent is given for each and every procedure/use, and that parents have easy access to the tissue removed. The lab or researcher DOES NOT own the tissue, the child does.

My son has a brain tumour, my daughter has had 3 liver transplants yet there is no recognition for our children who had to be transplanted for an incurable genetic disorder.

If a tissue is required, it should be only taken with informed consent. Some parents may be comfortable with it, while others might not be comfortable. Using a blanket rule has the potential to cause emotional turmoil to some parents.

3b Amend the *Transplantation and Anatomy Act 1979* to remove the requirement that a post-mortem examination of a body conducted in a hospital only be held in the hospital mortuary.

Health Consumers Queensland supports this amendment with the understanding that current post-mortem practices limit the opportunity to undertake less invasive procedures resulting in a reduced number of families agreeing to invasive post-mortems.

We wanted to know if people would give consent for a more non-invasive post-mortem examination if it was available and the response was overwhelmingly in favour.

Question 1: would you be more likely to give consent for a non-invasive post-mortem examination for your family member if that option was available?

YES	**92.06%**
NO	7.94%

Supportive

Cultural safety and appropriateness may be enhanced for Indigenous people and other cultures, does the family receive a full report?

This would also meet the needs of Muslim community members.

If a doctor told me a full autopsy was required and the reasons why, despite my own misgivings, I would likely give permission if there was a question over the manner of death. If imaging and scanning can avoid that, I would support it wholeheartedly

Didn't think there was any choice - unexpected death in young person is mandatory post mortem
It would be important to me that the numbers seeking this procedure didn't have implications for people living, who need scans and imaging i.e. delays to people requiring imagining for diagnosis or treatment/monitoring. It should not cause any delays to living patients.

Where I live, bodies are sent away for post-mortems. This may allow them to be done locally if required.

Provided that there is a guarantee that any invasive procedures will be carried out in a mortuary and nowhere else.

Make sure procedures are relevant for today's population when seeking permission for post-mortems.

This just makes good sense. Save the purchase of duplicate equipment.

This will fasten the process and is a great step taken in this direction of exploiting the technology for the better of mankind. Great work by the government on this one.

4. Amend the *Births, Deaths and Marriages Act 2003*, the *Coroners Act 2003* and the *Cremations Act 2003* to enable human body parts used for examination or teaching purposes in schools of anatomy to be lawfully cremated without a corresponding death certificate or the approval of an independent doctor.

Health Consumers Queensland agrees with the amendment with the understanding that the family is informed of this Amendment at the time of donation to schools of anatomy.

We also wanted to hear from consumers to see if they understood and agreed with the amendment.

Question 1: if a family member's body or body parts have been donated to a school of anatomy, or you are planning to donate to a school of anatomy do you agree with these amendments?

YES	**80.00%**
NO	20.00%

As long as the person donating is fully aware of the conditions of cremation/burial.

Yes, provided that there are internal processes in place to ensure only donated organs are disposed of.

Can this be written to the conditions of the original body donation that this is what will be done with the body/part when the time comes? That way family is unlikely to have a problem if the donor or family consents to that at the point of donation.

Once a body part is removed it's not the body anymore it's biological waste it should be treated with respect and disposed as such.

Not Supportive

Very uneasy about this provision: "an exemption from the requirements for burial or cremation under those Acts for part of a body used at a school of anatomy for the study and practice of anatomy." Does that mean that donated bodies or their parts can be held in perpetuity and used or disposed of at the inclination of the school of anatomy?

Conclusion

Health Consumers Queensland supports the proposed Health and Other Legislation Amendment Bill 2018 with consideration of further consultation prior to acceptance of:

Amend the *Transplantation and Anatomy Act 1979* to clarify the provisions about research that involve removing tissue from adults and children.