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Submission:

Amendments to the *Powers of Attorney Act 2006* (ACT)

Submitted by email to:

Gabrielle.McKinnon@act.gov.au

11 September 2019

Submission: Amendments to the *Powers of Attorney Act 2006* (ACT)

This submission has been prepared by the ACT Mental Health Consumer Network (The Network) in response to the invitation from the Legislation, Policy and Programs, Justice and Community Safety Directorate.

The Network is funded by ACT Health to be the peak systemic advocacy body for mental health consumers in the ACT. We represent the interests of mental health consumers in the ACT in policy and decision-making forums. The Network is committed to social justice and the inclusion of people with lived experience of mental illness. Run by consumers for consumers, our aim is to advocate for services and supports for mental health consumers which better enable them to live fuller, healthier and more valued lives in the community.

General Comments

In general, The Network supports changes to improve the ability of persons with impaired decision-making capacity to participate in medical research that may benefit themselves and others, subject to appropriate safeguards. However, we note that this is not unanimous and we attach a dissenting view from one of our members.

Consumers with lived experience of mental illness gathered earlier this week to discuss the proposal, and they raised a number of issues. These issues were then raised at the roundtable meeting you chaired on 22 August 2019. We summarise our position below.

The Network would like to emphasise that consent is a process, and not a single event. An individual's capacity to provide consent may change over time, as may their decision about that consent. Therefore, an adequate process includes repeatedly checking an individual's *capacity* to consent to participation, as well as their *decision* about consent for the duration of their participation in medical research. Following discussion at the roundtable, the Network supports the idea of seeking 'assent' from the participant, where this is possible, not just consent from the individual's Power of Attorney. We feel that the need to seek assent, or firmly establish the absence of dissent, adds a valuable level of protection for consumers.

The Network would also like to see the term 'clinical trial' defined in the Act. At the roundtable, Professor Paul Gatenby explained that this definition would probably align with 'Phase III trials'.

> *Phase III studies are done to study the efficacy of an intervention in large groups of trial participants (from several hundred to several thousand) by comparing the intervention to other standard or experimental interventions (or to non-interventional standard care). Phase III studies are also used to monitor adverse effects and to collect information that will allow the intervention to be used safely.*[1]

However, we feel there is also a need to specify in the Act what else might fall into this low risk category.

Finally, we would be grateful to receive a copy of the research, which Professor Gatenby cited, demonstrating that participants in clinical trials receive better care than those who are non-participants.

Thank you once again for the opportunity to provide comment and we look forward to hearing how you intend to proceed.

[1] https://www.australianclinicaltrials.gov.au/what-clinical-trial/phases-clinical-trials

Attachment

From:
Sent: Saturday, 17 August 2019 12:44 PM
To: ACT Mental Health Consumer Network
Subject: Re: POLICY FORUM INVITATION: Amending the Powers of Attorney Act

Hi there

I have very strong opinions on this issue.
This amendment cannot go ahead!

Its removal was the result of years of advocacy. It is completely wrong to be legally testing medicines on people who are unable to provide informed consent. The rest of the population can do that. Mental health consumers under the Act need protection. Allowing any clinical trials at all (regardless of their 'official risk classification', deemed by an ethics committee) adds financial incentives into the public mental health system in a dangerous way. The detained consumers are effectively guinea pigs for pharmaceutical companies without the right to decline.

Before the amendment was formalised (removing the right to hold clinical trials on consumers), very vulnerable consumers had severe adverse effects in these trials. Completely hidden and unhelped. Their symptoms were so extreme and rugged as the medicines were still being refined. We can't let that happen again.

Please use the above as you see fit. As my formal submission to the consultation, by proxy and in writing; from an organisational email address (to be sure of authenticity).

Sincerely