Australian Psychological Society

Hon Dr Sally Talbot MLC
Chair, Standing Committee on Legislation
Legislative Council Committee Office of Western Australia
18-32 Parliament Place
West Perth WA 6005

Level 11, 257 Collins Street
Melbourne VIC 3000
PO Box 38
Flinders Lane VIC 8009
T: (03) 8662 3300
F: (03) 9663 6177
www.psychology.org.au

Via Email: lclc@parliament.wa.gov.au

8 June 2020

Dear Dr Talbot,

RE: Inquiry into the Guardianship and Administration Amendment (Medical Research) Bill 2020

The Australian Psychological Society (APS) thanks the Standing Committee on Legislation for the invitation to provide a written submission on matters relating to the scope, purpose, and structure of the Guardianship and Administration Amendment (Medical Research) Bill 2020.

We understand that the purpose of this Bill is to amend the Guardianship and Administration Act 1990 to provide the authorisation and appropriate safeguards to enable enduring guardians, guardians and next of kin to consent to medical research for people under legal incapacity.

Essentially, this Bill will allow doctors to participate in trialling new and emerging treatments. Under existing legislation, an enduring guardian (or next of kin) is able to make a decision about medical treatment, but not medical research. The Bill has been tabled, quickly, in response to issues that have arisen in light of COVID-19.

Currently, 'incapacitated' patients do not have access to COVID-19 treatments, which may be on trial in other parts of the world. The amended legislation will enable doctors to offer treatment beyond what is currently available to those patients with COVID-19 who are unconscious and/or cannot make decisions for themselves. We understand that this legislation is expected to benefit all critically ill Western Australians to access drugs and treatments that are being tested in other countries to give them the best possible chance of recovery from COVID-19 and any other future diseases.

Despite the potential benefits of the legislation for patients as described above, the APS is concerned about the speed with which this legislation has been developed. This is a very complex piece of legislation which necessitates time and consideration. Fortunately, to date, Western Australia has a relatively low number of confirmed COVID-19 cases compared to other parts of Australia and internationally. In light of this, the Committee may deem it worthwhile to spend

more time to seek expert opinion, ensuring this important piece of legislation is as good as it can be.

While much of the detail of this Bill is beyond the scope of APS expertise, the issue of consent, which strikes at the heart of this legislation, is core to our profession. The APS has a number of concerns regarding the legislation which will be described in more detail.

It seems both reasonable and acceptable to extend the ability of the guardian or enduring guardian, to make decisions about medical research, because their appointment is governed by law and in some cases the research candidate would have given authority to them to make decisions. However, a more controversial aspect is that this would often not have included giving consent for participation in research, but it is likely that most people would have given consent for research that might be beneficial to them.

Another concern for the APS is the substitute decision-makers and whether they will act in the best interests of research candidate. However, it looks like there is enough detail in the relevant sections, specifically the order of priority that will be applied in determining who is a substitute decision-maker, to alleviate these concerns.

Our biggest concern is section 110ZS(1)(c) that allows research without consent. It is stated that:

> "A researcher may conduct medical research in relation to a research candidate if —
> …
> (c) the candidate is unable to make reasonable judgments in respect of their participation in the research"

This raises the question about whether the Guardianship and Administration Act provides any criteria that specifies when a candidate will be considered to be unable to make reasonable decisions. The Voluntary Assisted Dying Act, albeit in reverse, is a good example of legislation that provides clear criteria about when a person has decision-making capacity (see section 6(2)).

The next critical question is, who makes and checks this decision. Most lead researchers will not have special expertise in this regard and the 'independent' medical practitioner (sections 13 and 14), who appears to be the check and balance (on the basis of having no conflicts of interest) does not seem to have any qualifications to assess decision-making capacity.

With reference again to the Voluntary Assisted Dying Act (Section 26), if the coordinating practitioner is unable to determine whether the patient has decision-making capacity then the practitioner must refer the patient to "a

registered health practitioner who has appropriate skills and training to make a determination in relation to the matter".

While the Voluntary Assisted Dying Act works the other way around (in that it seeks to determine whether a patient has, rather than doesn't have, decision-making capacity), the APS recommends that the Guardianship and Administration Act should follow the general legal presumption that people have decision-making capacity and that it should be "a registered health practitioner who has appropriate skills and training to make a determination in relation to the matter". This independent health practitioner will therefore decide that the patient does not have decision-making capacity and therefore make the final call that the research can proceed without consent.

The APS is pleased to see that the Bill has a range of safeguards in place to uphold the rights of the person. This includes a review of the amendments after two years to address any unforeseen issues that may have arisen due to the speed and urgency with which the legislation has been amended.

The APS is also reassured to see that the Bill specifies that under no circumstances can consent be given for research that is a procedure of sterilisation or electroconvulsive therapy.

This amended legislation will make it even more important for people to consider, and make it explicit in advance, who they appoint to make not only medical decisions on their behalf, but also decisions about medical research. Ideally this information would also be recorded in an advance health directive, but we understand that this is not always available.

In summary, the APS supports the purpose of the Bill which is to assist people who are critically ill to take part in research trials and potentially have access to life-saving treatment. However, we are concerned that the speed with which these amendments have been made could potentially have overlooked some important considerations that may mean the best interests of the person are not at the forefront.

The Draft Amended Act presumes that the research candidate does not have decision-making capacity. This presumption is acceptable when the research candidate has a guardian or substitute decision-maker who can provide consent. However, this assumption is a concern when there is no guardian or substitute decision-maker involved in the process and urgent medical research occurs without consent. In this instance, the APS recommends putting in place appropriate measures to ensure that research, in the absence of consent, only proceeds if an independent medical practitioner has the appropriate skills to determine decision-making capacity (or if not, has access to an appropriately trained registered health professional).

Thank you again for the opportunity to provide feedback.

Yours sincerely,

Ros Knight
President

Acknowledgments
Prof Alfred Allan PhD FAPS, Edith Cowan University