GUARDIANSHIP AND ADMINISTRATION AMENDMENT (MEDICAL RESEARCH) BILL 2020

Introduction and First Reading

Bill introduced, on motion by **Mr R.H. Cook (Minister for Health)**, and read a first time.

Explanatory memorandum presented by the minister.

Second Reading

MR R.H. COOK (Kwinana — Minister for Health) [12.42 pm]: I move —

That the bill be now read a second time.

The government of Western Australia has declared a state of emergency and a public health emergency in response to COVID-19 and severe changes have been rolled out across the community to assist in stopping the spread of COVID-19. The state government is acting on the best medical advice in the country, but as a government we can do more to help our medical community and those patients who are suffering in their fight against COVID-19.

Currently in Western Australia, if a person has lost capacity to make his or her own decisions, even if for only a short period, medical practitioners are not authorised to seek consent for medical research from a patient's enduring guardian, guardian or next of kin. This, effectively, denies critically ill or otherwise incapacitated COVID-19 patients access to the cutting-edge treatments that are on trial throughout the world. If we are to provide the best health care possible for Western Australians, we must keep pace with the various treatment responses that could save our most vulnerable COVID-19 patients from serious harm or death.

The Guardianship and Administration Amendment (Medical Research) Bill 2020 provides critical legislative amendments that will enable our doctors to join the global effort to trial new and emerging treatments for COVID-19. Considerable efforts are underway worldwide to provide effective drug treatment for COVID-19. The World Health Organization is launching a multi-country clinical trial to test four drug regimens as COVID-19 therapies. A similar multi-country trial is taking place in Europe. Hundreds of other treatment trials are underway. Some COVID-19 patients are already receiving drugs that are the subject of clinical trials through compassionate-use programs. These programs allow doctors to order experimental medications in certain cases and for those medications to be used for purposes outside of what they have been approved for.

We need treatments that will slow or kill the novel coronavirus. We need to know what treatments are most effective so that we can reduce the time patients spend in hospital, particularly in intensive care. This knowledge can be gained only through medical research. Thirty-five companies and academic institutions around the world are exploring potential vaccines, including a team at the University of Queensland. One company has started human trials and another three claim to be close. However, experts are warning the population to be patient, with World Health Organization officials maintaining that a vaccine will not be available before the middle of next year. Human trials are essential to the development of a vaccine.

Last week, members would have heard Dr Andrew Miller, the president of the Australian Medical Association Western Australia, state that if Parliament does not pass amendments to the Guardianship and Administration Act 1990, our doctors and hospitals cannot offer all Western Australian COVID-19 patients a chance to benefit from the trial therapies that are being used around the world. Dr Miller is right. All Western Australians must be able to access the drugs and treatments that are being tested in other countries to give them the best chance possible for recovery. While many other Australians will benefit from rapidly advancing treatments, even cures, Western Australians under legal incapacity would be unable to do so. Currently, Western Australia legislation enables an enduring guardian, guardian or a person responsible to make a decision regarding medical treatment, but this does not extend to participation in medical research.

If a person has lost the capacity to make his or her own decision about medical treatment, even if only for a short period, the Guardianship and Administration Act 1990 authorises a person responsible to make treatment decisions on their behalf. If a person has not completed an advance health directive or appointed an enduring guardian or guardian, a person responsible is the first person in order of the priority prescribed in section 110ZD of the act who is of legal capacity, is reasonably available and is willing to make a treatment decision at the time the treatment is required. The order of priority is, first, the patient's spouse or de facto partner if that person has reached 18 years of age and is living with the patient; second, the patient's nearest relative who maintains a close personal relationship with the patient; third, the person who has reached 18 years of age and is the primary provider of care and support to the patient but is not remunerated for providing that care and support; and fourth, any other person who has reached 18 years of age and maintains a close personal relationship with the patient. This order of priority is more commonly referred to as next-of-kin consent.

The problem with the existing legislation as highlighted in the COVID-19 pandemic environment is that persons responsible are authorised to make only treatment decisions. For the purposes of the Guardianship and Administration Act 1990, treatment means medical or surgical treatment, including a life-sustaining measure and palliative care; dental treatment; and other health care. The act does not authorise enduring guardians, guardians or next of kin to consent for patients to participate in medical research, including drug and treatment trials. This overlooks the continuum between treatment and research, which exists in many cases. A single patient may be treated in his or her best interests—or in a way that is, at least, not adverse to their interests—but the treatment is also part of larger research for the community's benefit.

In 2015, a statutory review of the Guardianship and Administration Act 1990 recommended that the legislation be amended to enable a person responsible to make a decision on behalf of a person, for that person to participate in medical research, including treatment that is part of research, in certain circumstances, including if it is in their best interests to do so, considering the risks involved, human research ethics, and other factors. The statutory review was tabled by the Liberal–National government in 2015, but no action was taken to implement the recommended legislative amendments to the Guardianship and Administration Act 1990. Although the McGowan government recognises the importance of implementing all the supported recommendations from the statutory review, the recommendations dealing with consent to medical research are, in the current environment, crucial. The amendments in the Guardianship and Administration Amendment (Medical Research) Bill 2020 will ensure that all Western Australians have the opportunity to participate in world-leading research and experimental treatments specifically targeted at combating the COVID-19 coronavirus.

I will outline the bill's key amendments, which will, in brief, allow enduring guardians, guardians and next of kin to consent to medical research and, in emergency circumstances, enable an independent medical practitioner to authorise research without consent, subject to strict safeguards and stringent conditions to protect the person.

The bill will insert new Part 9E, which relates to medical research. Medical research is defined as research conducted with or about individuals, or their data or tissue, in the field of medicine or health. Medical research will include research activities such as the administration of pharmaceuticals or placebos, the use of equipment or a device and the provision of health care that has not yet gained the support of a substantial number of practitioners. The bill provides an order of priority of persons who will be able to make a research decision about a person. This person is referred to as the research decision-maker. The order of priority detailed in the bill will authorise a person responsible to make a research decision. If a person has not appointed an enduring guardian or a guardian, a person responsible is the first person in order of priority who is of legal capacity, is reasonably available and is willing to make a research decision at the time the research decision is required. The order of priority will mirror the current next-of-kin consent for treatment decisions.

The bill ensures that a research decision-maker cannot consent to a person participating in the medical research unless the research is in the best interests of the person or is not adverse to the interests of the person. If the research goes beyond observation or non-invasive examination, treatment or procedure, then the research decision-maker cannot consent to participation unless the research will not involve any known substantial risks to the person; any known substantial risks greater than the risks associated with existing treatment; or any substantial risk greater than if the person did not participate in the research.

The principles of the Guardianship and Administration Act 1990 revolve around best interests and respect for a person's wishes, and the bill ensures the amendments have regard to these principles. The bill inserts a new section that prescribes the factors that must be taken into account when determining whether participation in medical research is in the best interests of the person. The bill provides that the following factors must be considered: the wishes of the person; the likely effects of participation, including the existence, likelihood and severity of any potential risks, and whether those risks are justified by any likely benefits of the research; any other consequences if the person is not involved in the research; any alternative treatments available to the person; and any other prescribed matters.

The bill clearly states that, when making a research decision, the research decision-maker must regard the wishes of the person as the paramount consideration. If a person has an advance health directive in place that specifies his or her wishes about participation in medical research, or particular types of medical research, following this directive will be mandatory.

If a person requires treatment urgently to save the person's life, prevent serious damage to the person's health, or prevent significant pain or distress, and it is not practicable to obtain a research decision from a research decision-maker within an appropriate time frame, the bill permits a researcher to carry out research approved by a human research ethics committee. However, this can occur only if an independent medical practitioner has determined that a person is incapable of making reasonable judgements about research for themselves, and if an independent medical practitioner has determined that the research is in the best interests of the patient, or is not adverse to the interests of the patient by increasing his or her medical risks.

In order to access these provisions, and make a research decision without consent, the medical research must meet the following stringent conditions. The research must have been approved by a HREC; the HREC approval must have been provided with the requirement for prior consent; the research must be in the context of urgent care.

In addition, to make a research decision without consent the person must be unable to make reasonable judgements about their participation in the research; in an independent medical practitioner's opinion, the person is not likely to regain capacity to give consent within a time frame specified by the HREC; it is not practicable to obtain consent from a person responsible; and participation in the research does not involve any known substantial risks to the candidate, or any substantial risk greater than the risks associated with existing treatment.

Critically, in addition to these factors, an independent medical practitioner must confirm that the person's participation in the research is in the person's best interests or is not adverse to their interests. As is required for medical research with consent, the bill clearly states that when making a research decision in an emergency situation, an independent medical practitioner must regard the wishes of the person as the paramount consideration.

The State Administrative Tribunal is to be vested with additional powers to ensure that a person may apply to the tribunal for review of a decision made under the medical research provisions. The review process will engage the various powers of the tribunal contained in the State Administrative Tribunal Act 2004. The policy is that the tribunal may review a decision about whether research is in the best interests of a candidate, or whether a candidate is able to make reasonable judgements about undertaking the research. If the tribunal considers that a review is warranted, it may, effectively, set aside a decision made by a research decision-maker or a researcher, but only with prospective effect, and without affecting the validity of anything done by a researcher in reliance upon the decision prior to the tribunal's decision. That protects the researcher acting upon the basis of a research decision, but allows the prospect of the tribunal intervening to correct research decisions that ought not to have been made. Obviously, this will be important for research that has yet to be carried out, or has been only partially carried out.

The right of review will be of less utility in cases if the research has been wholly carried out in urgent circumstances prior to the opportunity for a review application to be made. However, in the last case, the policy balance between the need for an urgent decision and urgent action, and any need for review of that decision by the tribunal, falls upon the side of allowing the urgent decision to be made and implemented in accordance with the safeguards that are already provided in Part 9E.

Finally, a review clause has been included that requires that the operation and effectiveness of the amendments made by the bill be reviewed after two years, with the resulting report to be tabled in Parliament. The state government recognises that due to the urgency presented by the coronavirus, consultation on the bill has not been as comprehensive as we would like. Consequently, the review clause is essential as it will enable the amendments to be reviewed, with wide input from medical and consumer stakeholders, to ensure the policy intent of the amendments are workable on an operational level. I have also written to the leaders of the other parties, as well as the spokesperson for Health in the WA Greens, to indicate that I would support a reference to the Education and Health Standing Committee for it to undertake its own review to feed into the statutory review just mentioned.

The bill does not enable participation in medical research as a general blanket provision but, rather, ensures specific consideration of a number of factors relevant to each individual situation. The bill maintains a balance between the considerations of the best interests of the person and at the same time will ensure that our medical practitioners can make research decisions in time-critical emergency situations. It is supported by significant safeguards to uphold the rights and protections of the person, it contains an avenue for review by the State Administrative Tribunal, and it requires a comprehensive statutory review of the amendments after two years.

Most critically, the bill authorises a person responsible to make a research decision on behalf of a person who has no legal capacity. We need to make these amendments our highest priority to ensure that our most vulnerable Western Australians have the opportunity to access the experimental treatments being trialled to combat COVID-19. To delay these amendments any further will only deny Western Australians the opportunity to receive potentially lifesaving treatment during this pandemic.

I commend the bill to the house.

MR P.A. KATSAMBANIS (Hillarys) [1.01 pm]: I rise as the lead speaker from the Liberal Party to speak on the Guardianship and Administration Amendment (Medical Research) Bill 2020. We are in extraordinary times. I do not use that term loosely; I use it in a completely different context to the times are extraordinary, but we are dealing with extraordinary circumstances in the way that this bill comes to the house. I will get to that during my presentation.

The government has proposed this bill as part of a suite of legislation that it would like to pass in this place to address issues related to responding to the COVID-19 pandemic that is before us. We all want to be as facilitative as possible in passing any urgent legislation that is necessary. However, unlike other bills that have come before this house this week, this bill is not time-limited in any way, and it is not limited to providing powers or authority

in relation to emergency circumstances that we confront in dealing with the pandemic before us. This bill will amend a very substantial piece of Western Australian legislation, the Guardianship and Administration Act 1990, for the ongoing future—until it is amended again. These powers will come into place forever and a day until a future Parliament considers them again and amends them. In that context, it is critically important that we get the legislation right and that it is appropriate for its intended purpose. It becomes even more critically important when we deal with an act such as the Guardianship and Administration Act which, as the name suggests, provides a way for people who may be under some form of incapacity to have someone else represent their best interests in the administration side, their financial interests and associated interests that go along with finances, and, in relation to guardianship, in decision-making more generally, including decision-making about medical treatment.

The provisions are cumbersome in some cases, but they are tried and tested—they work. They work by providing a framework for people, when they have capacity, to appoint someone to look after their interests, whether it is in guardianship or in administration, or both. When someone loses capacity without an appointment, or when an appointment is no longer able to be executed in some way or another after someone has lost capacity—for example, after a husband gives power to his wife, the husband loses capacity and the wife continues either in guardianship or as a power of attorney but the wife subsequently loses capacity—there are provisions in the act to deal with all of those sorts of things. There is a framework to appoint someone to act in place of a person who cannot act because of an incapacity.

As I said, that carries through a range of situations including financial and personal decisions around where and how they live, and in relation to medical treatment. We also have the interplay in our system of advance health directives so that an individual, whilst they have capacity, can give very clear instructions about what sort of health and treatment interventions, if you like, they would like if at any stage they lose capacity. It is a very well established framework. As the Minister for Health rightly pointed out, the framework is comprehensive, but it is not complete. It is incomplete in how we deal with an individual who is incapacitated and may be a candidate to undertake medical research as opposed to medical treatment. If the research were treatment, it would be covered by the term "treatment" that is already in the act. But we are talking about something that may have some elements of treatment to it, but primarily is research rather than treatment. There may be benefits and there may be treatment associated with research.

As the minister rightly pointed out in his second reading speech, this issue was raised in the "Statutory Review of the Guardianship and Administration Act 1990", which was tabled in this place in December 2015. A series of recommendations were made. I have a copy of it here. In the circumstances in which we are working this week, it is rather difficult to refer to all of my notes. Eighty-six recommendations from the review have been sitting on the table of the house since December 2014—more than four years—across two governments, admittedly, but this will be the first recommendation to be implemented, which is recommendation 6. If we are kind, we will say it implements two, because recommendations 6 and 7 can be read together. This bill will implement two of the 86 recommendations from that review. They are being brought in because, obviously, as is spelt out in the second reading speech and was pointed out in the media, when we are confronted with a novel disease, something that we have not known about before, research is an absolutely essential part in working out how best to protect ourselves, how best to immunise against it, and how best to treat it and maybe cure it. We are all working for a common purpose. The gap was identified by the statutory review. It had been known beforehand but it was identified to government and to Parliament by the statutory review. The statutory review considered submissions made to it on how best to provide a framework for people to be given the benefit of research if they have not given or are unable to give consent to research, especially at a critical time when they might need it most. Many groups made submissions to the review. The Public Advocate made a submission. The Department of Health made a submission. A joint submission was made by various human research ethics committees based in Perth. Research Australia made submissions. The Australian Medical Association (WA) made submissions, and I think Hollywood Private Hospital also made submissions. The reviewers weighed up those submissions and made recommendations. They essentially recommended—I am paraphrasing—that the first element of what the government brought to this place today be implemented but with an overriding framework, as set out in recommendation 7, that "research" must have the same definition as in the "National Statement on Ethical Conduct in Human Research" prepared by the National Health and Medical Research Council, the Australian Research Council and the Australian Vice-Chancellors' Committee. These bodies said that there ought to be a framework in which a person standing in the place of the incapacitated individual can consent to medical research being performed on that incapacitated person. The framework was largely the framework that was spelt out by the minister and is contained—I am trying to get to the page because the first time I saw this finalised bill is when the minister made his second reading speech—in proposed section 110ZR, under division 2 of part 9E, which is being inserted into the act. Under that part, there is the equivalent of a next of kin. Either there is an enduring guardian or a guardian or there is a line of next of kin—spouse, children, close personal relationship and the like. The reviewers then turned their minds to what would occur in circumstances in which those people are not available to give that consent. Can there be a circumstance in which research can

be applied to an incapacitated person without consent? The reviewers said no. Recommendation 6.2 was very clear, stating —

> Health professionals acting under the urgent provisions in sections 110ZI and 11OZIA will not be permitted to make a decision on behalf of a represented person for that person to participate in medical research, including treatment that is part of research.

Quite clearly, the statutory reviewers said, "We believe that is going further than what we think is appropriate." That was the recommendation the statutory review made to this Parliament. In making that recommendation, I am sure they focused significantly on the comments made by the Public Advocate. Page 5 of the statutory review states —

> The Public Advocate supports the concept of a guardian having the function to allow a represented person to participate in such trials, however the wellbeing of the represented person must be the primary focus and consent should only be given where it is clear there will be no detrimental impact on the represented person and in all likelihood they will benefit from participation in the trial. If a trial includes a participant receiving a placebo rather than active treatment, it should not be possible to consent as such a trial could result in the represented person receiving no treatment which could not be seen to be in their best interests and would therefore not accord with the principles of the Act.

That introduces that concept of the principles of the act. It is very important.

The statutory review said that we should certainly introduce the first part that is being introduced today. I am talking about the part that allows people who usually consent to medical treatment on behalf of an individual who cannot give consent, being the guardian, the enduring guardian or a family member or hierarchy of selections, to give consent for research as well. As the second reading speech stated, the order of priority is more commonly referred to as next of kin consent. But the statutory review said that we should not go down the path of extending that consent to medical practitioners making that decision on their own without the involvement of family members or next of kin. We are talking about an incapacitated person. We can all debate whether that is the right outcome or the wrong outcome but that recommendation was made by a statutory review that conducted a public review on the act.

Coming full circle, four and some years later, the government has brought forward this bill that introduces that principle that the statutory review recommended against. It introduces a framework, which I will get to if I have time. How will it introduce it? Will it undertake another review—another opportunity for public consultation? Remember, we are putting in laws that will apply forever and a day until they are amended again. We are not putting them up for an emergency time frame or a time-limited time frame; they do not sunset. If this bill passes, these laws will exist until we turn our minds to them again as a Parliament. Given the amount of time it has taken from the statutory review to now, the public can understand how long that might be sometimes. There was no public consultation on these important provisions dealing with perhaps one of the most vulnerable groups, if not the most vulnerable, in our society. We are talking about an incapacitated person who is in need of urgent medical treatment—a person who cannot make a decision for themselves and is so ill, they need urgent medical treatment. They are probably equal to many other vulnerable groups in our society but they are amongst the more vulnerable people in our society.

This bill has been introduced. The opposition was told late last week that this bill would be coming up. We were given a draft copy of the bill on Monday. Today is Wednesday. That copy of the draft bill was marked draft 14. It was dated 29 March. Obviously, someone had been working hard at it on the Sunday and we got it on the Monday. That is fair enough. We are dealing with emergency circumstances; I recognise that. This morning we were given a copy of draft 21 of the bill, dated today. During those three days, there had been seven more drafts. Again, I recognise that some of those drafts may well have been drafting errors. At about 10.30 this morning we were given a marked-up copy that purported to show all the differences between draft 14 and draft 21. Of course Parliament started sitting at 12 o'clock and during that interregnum, we were having a briefing on this bill, for which I thank the minister and the various staff; it is a combined effort involving staff of the Attorney General and the Minister for Health. Now we have this bill dealing with the most vulnerable group in our society, and this subject matter will enable medical practitioners to make a decision without the consent of anyone other than themselves and a circle of medical practitioners. I am not casting aspersions on them; that is what it does. I am not criticising that, but that is the framework that is proposed here. A series of medical practitioners will get together and say, "This research says it is good for the patient, so we're going to give it to you." No consent is required from the patient or from any next of kin.

I do not know whether this bill is draft 21 or draft 22—or draft 21 and a half. I have not even had a chance to compare it with the last draft I was given at 10.30 am. The minister brings it in, reads it in, and we are expected to respond. This is where I will digress for a minute. In question time, the Premier answered my question and I was comfortable with his answer, but he went on a tangent and started attacking members of the Legislative Council for supposedly being overzealous in their scrutiny of legislation. I am sorry, but we do not criticise people for doing their job, especially in the context I have just outlined. They will have to do that with this bill too. They will

have no choice, because we have had no choice. I have not even had a chance to draw breath between the time the minister finished his second reading speech and tabled the explanatory memorandum to the bill and I started responding to the minister to provide the opposition's response to this critically important bill. Yes, we are in difficult and extraordinary times. Yes, we want to introduce the best possible legislation to protect our people, but part of protecting the most vulnerable people is to make sure that the legislation is good and correct. We are not being afforded that opportunity. Not only that, we are being lectured about delaying legislation. Delaying it? This legislation has been sitting on someone's desk in the former Barnett government and in this McGowan government for more than four years. It has been sitting there gathering dust in both governments. Shame on all of us, really. When there has been public consultation and a report has been presented advising not to do something, and this legislation does the something we were told not to do in the public consultation, the statutory review, are we meant to just ignore it and shove it aside? Is that good government for the people of Western Australia? Is that good government for the most vulnerable people in our society?

I am not sure which minister arranged the briefing. It might have been the Minister for Health or it may have been the Attorney General. Irrespective of that, it was useful. All of the briefings arranged by the government are very useful, especially in this period. At a briefing arranged this morning, Professor Daniel Fatovich, a highly credentialed eminent researcher, indicated clearly that this bill will have some relevance to researching COVID-19. However, he made it very clear that the broader application will be in other areas of medical research, and that is understandable. People are conducting research now into COVID-19 all over the world. There is no doubt that we can play a part in that. We have great people here—absolutely wonderful people here. When this fight against COVID-19 is won—I am an optimistic person; I know it will be won and it will be won in a relatively short time frame—this bill will continue to exist and it will guide research in this state into all sorts of other areas. That is what the good professor told us, so we need to get it right.

Let us turn to some of the provisions and protections in this bill. I am not sure whether I made it clear at the outset, but the opposition does not oppose this bill. We are just concerned about the haste with which it has been introduced and the lack of public consultation around doing something that the last public consultation told us not to do. We had a briefing on this bill. The days tend to meld into each other. I think the member for Cottesloe attended our first briefing on this bill via teleconference. He will be able to remind me. Was it on Monday evening that we had a briefing on this bill?

Dr D.J. Honey: I believe so.

Mr P.A. KATSAMBANIS: It was an important briefing. We raised a number of issues about how the technical aspects of the bill work. That was draft 14 that we were looking at. In draft 21, a number of those concerns appeared to have been dealt with. One of those concerns was: where does an advance health directive sit in relation to authorising medical research? If an individual has an advance health directive in place, the draft we saw on Tuesday indicated that it would be treated as a paramount consideration but—and there were a whole lot of buts. In the draft I saw this morning, that had been cleared up. I have not had a chance to compare that draft 21 with the bill that has been presented in the house. Can the minister, by interjection, at least tell me whether it is exactly the same? Is this bill before the house exactly the same as draft 21 that was provided to us mid-morning?

Mr R.H. Cook: Yes, it is.

Mr P.A. KATSAMBANIS: It is; okay. That is great. That issue had been cleared up, because the original drafting, which we were told was done well, had a circumstance in which an advance health directive, the directive an individual had given whilst they had capacity about what happens to them in case they are incapacitated, could have been overridden. That has been tidied up. The minister spelt that out in his second reading speech, and I am glad that is the case. I quote from my page 4 of the second reading speech —

> The bill clearly states that, when making a research decision, the research decision-maker must regard the wishes of the person as the paramount consideration. If a person has an advance health directive in place that specifies his or her wishes about participation in medical research, or particular types of medical research, following this directive will be mandatory.

That is absolutely as it should be, but it was not the case on Monday evening when we were working through this bill. That is one of the areas that was tidied up.

Another issue was around the independent medical practitioner as outlined in the bill. The term "independent medical practitioner" is clearly defined, and that person has a very important role to play in advising both the next of kin in their decision-making and, more particularly, a medical researcher in their decision-making. The position was unclear as to whether it could be filled by one of the treating medical practitioners of the patient, the potential subject matter of the research. In actual fact, any logical reading of draft 14 would suggest that one of the treating doctors would sign off on it, which I believe was a failure rather than a positive because it brought into question the

independence of the medical practitioner providing the independent medical advice on the research that is being proposed. That had been fixed fairly well in draft 21 from my reading of it. I cannot speak about the bill before me, but I am told that it is exactly the same, so I will take that as it is intended.

Another important issue that I raised at the briefing was that the term "urgent care" used in proposed section 110ZS is not defined in either the bill or the primary legislation and, as far as I am aware, is not defined in any context relating to the Guardianship and Administration Act. It may be defined in some sort of health regulations and the like, but it certainly has no application to this legislation whatsoever. I pointed out that there is a definition of "urgent treatment" in part 9D of the primary act, and I was given a longwinded explanation of why they are different and why that definition ought not to be incorporated to the proposed section that provides for urgent medical research without consent. I was left to believe that that probably could not be fixed, but, lo and behold, when I looked at the marked-up version of draft 21 this morning, I found that proposed section 110ZS had been amended, "urgent care" had been removed, "urgent treatment" had been included and "treatment decision" had been better defined. Interestingly, proposed section 110ZS(1)(b) states —

> the candidate requires urgent treatment as defined in section110ZH …

All of a sudden, between Monday and Wednesday, it became possible and, not only that, it became preferred. I do not say any of that to suggest that I am smarter or better or brighter than anybody else; in fact, I am not.

Mr P.J. Rundle: That's true!

Mr P.A. KATSAMBANIS: Which part?

I just say that to point out how additional scrutiny of this complex area is good, even under extenuating circumstances in which a briefing is conducted and, within a few minutes, a response is sought immediately, and that is what we are doing right now. It improves the legislation. We end up working through this as quickly as we possibly can and we improve the legislation. This is a much better bill than the bill that I saw on Monday evening. That is the result of everyone's work. It just addresses the technical nature of the bill; it does not overcome those broader deficiencies around appropriate public consultation and doing something that the previous public consultation said should not be done.

We are absolutely comfortable with the proposed sections that deal with medical research with the consent of research decision-makers. A series of things have been introduced into the legislation and two primary proposed sections give effect to the decision-making. Proposed section 110ZR requires the consent of the research decision-maker, and that research decision-maker will be in that hierarchy—I think of the enduring guardian, the guardian, the spouse, the next of kin and the like. That is all well and good. There is a robust process there. The independent medical practitioner will be more independent than they were previously. That is all good and proper. Our concerns are with urgent medical research without consent. To be fair to the opposition, in the context of what this legislation will do, it would have been appropriate to allow us some time to conduct consultation. Yes, we have heard from the medical researchers at the Harry Perkins Institute of Medical Research and the Honourable Wayne Martin, who heads that institute, and from Professor Daniel Fatovich and others. They are advocating that, and so they would and should. Anyone who holds a position in a medical research organisation would want to advocate for their organisation. They would want to advocate for broader powers to conduct research. Research is highly competitive. The minister knows that. One day, perhaps he and I might have a discussion about how I think Western Australia gets dudded in the allocation of research funding at the federal level, as we do in almost every other aspect.

Mr R.H. Cook: That is the purpose of the other bill that is in the other place at the moment. It is really around setting that up.

Mr P.A. KATSAMBANIS: Yes; I think that might have taken a bit of a back seat this week.

This state has shown its strength in all sorts of facets of medical research over many, many years. We are being dudded in our funding, and I understand that. I have no doubt that researchers, or those who represent researchers, would be advocating for more and better and wider research—open the gates. I get that. However, there are other interests to take into account, too. I have not been provided with any formal documentation from the Public Advocate. I could not attend the whole briefing this morning because I had a further briefing, but I was told that there had been another consultation process. I am not sure whether that was a public consultation process and who was consulted. One of the glaring omissions in the list of people I have been told have been consulted on this is the Law Society of Western Australia. "Why?", you ask. Who prepares all these enduring powers of guardianship, advance health directives and the like? Primarily, but not always, it is lawyers. The Law Society would have a valid point of view on this. It would also have a practical understanding. Perhaps there are other community groups that represent vulnerable people. I realise that we do not have a patient's rights advocate body independent of the Public Advocate, but other people would have a strong interest in having their say on whether we could conduct medical research on an incapacitated individual without consent. The opposition is hamstrung. I do not say this

pejoratively, but we have been given one side of the argument—the side of the researchers. I have no criticism at all of those people—good on them. They are strong advocates for their people, and good on them for advocating. But other people would have another view and we have not heard that, but we are being asked to pass this legislation today.

Interestingly, the minister said in his second reading speech that he is going to introduce a two-year review period. I do not like using Latin that often, but sotto voce, he said that he would also welcome a standing committee of this Parliament overseeing a review of the operations of the parts that are being introduced into the act in conjunction with that two-year statutory review. I am very uncomfortable with that. I think that when we allow medical research to be conducted on somebody who is incapacitated, without any form of consent from that person or their immediate family members, their next of kin, or anyone who is appointed by a court or tribunal to represent their interests, there needs to be, at an absolute minimum, continuing disclosure. I say at the outset—this is a personal opinion—that I am uncomfortable with proposed section 110ZS. I have no concluded view on it because I have not had a chance to form a concluded view. I believe that I have not had the appropriate consultation to form a concluded view in an area in which I am not an expert. I think that applies to most legislators here. However, I think that in this process, at an absolute minimum, we need some form of regular disclosure: How many? When? How often? What were the results? What were the outcomes? I would perhaps go a bit further and suggest that any person who receives this urgent medical research without consent and who unfortunately dies during the period of research or some genuine time afterwards, ought to be submitted to a coronial investigation. Minister, I know that you are in and out; it is that sort of time.

Mr R.H. Cook: Sorry.

Mr P.A. KATSAMBANIS: I was saying that I think that two years is simply not good enough; it is not good enough to introduce a clause such as this. I think we need a better reporting framework—to Parliament—for scrutiny of this, as an absolute minimum, even were we to overcome any threshold issues around whether we should be doing this or not. That is the sort of stuff we could have done in a broader overview if this legislation was being not rushed in today. I appreciate that the medical community want it. The best outcome, without doubt, would be to bring in proposed section 110ZR and allow that to happen so that anyone who has COVID-19 at the moment and who can give consent can give consent now. But if they have capacity to consent, this bill does not apply to them. If they do not have the capacity to consent, there is a family there—a guardian, an enduring guardian, a spouse or a child. We have modern communications nowadays. Someone may not be present in the state or country, but we can communicate with them really, really, really urgently. We can communicate with almost everyone.

Unfortunately, we are living a period in which we know where most people are right now. They are not travelling; I do not want to be glib about it. Therefore, I do not think that obtaining that sort of consent is onerous on a researcher. Remember, we are distinguishing treatment from research, because if this were pure treatment, it would already be covered. This is separate from ordinary treatment; this is research. There might be treatment that is associated with research. I think had we allowed that and then this novel section that was specifically recommended against by the statutory review been considered in isolation by a parliamentary committee or simply by putting out a green bill and asking the public to comment on it, that would have been the best way to go. We could have done that without introducing proposed section 110ZS. One or two people might have missed out on research—potentially, maybe. I do not know. I do not want to say that I think so; I just do not know. But a vast majority in the ninetieth percentile clearly would be covered if this section did not exist in the bill, absolutely, especially with modern communication. I do not think that it is at all an onerous obligation on a researcher to find out who is the next of kin and to give them a call. Usually, we know that with seriously ill people, their loved ones—spouses, partners, grandparents and grandchildren—are keen to know. They are not absentee; they are there. They want to know. We could have done it that way, but clearly the government has chosen to go down this pathway so that it is subject to scrutiny. It is going to have to be subject to scrutiny.

I have to say that I feel like a failure in my duty as a legislator because I cannot properly scrutinise this legislation. Look at it. The government has brought it in. The government has put it on the table and I have picked it up and started talking about it. Yes, I have had the opportunity of a couple of briefings and a couple of drafts over the last few days. That is great and it is really critically important, but that is without addressing the issue about what research without consent will actually look like in practice and without addressing the issue of how placebo research fits into this, something that the Public Advocate specifically focused on in their submission to the statutory review. I know things have changed, and I am told that the Public Advocate has a bit more comfort since 2015, but I have not had the opportunity to get that in writing or even speak to the Public Advocate to know whether that is the case.

How would placebo treatment or placebo research happen? If treatment is being conducted, treatment is being conducted. At some point someone decides, whether urgently or non-urgently, that the existing known treatments are not working or they are not working as well as they ought to be and perhaps something experimental, some

form of medical research—experimental research, as was stated in one of the drafts of the explanatory memorandum that I read—will need to be conducted on a person. That is all well and good. We will have one group that gets the research and another group will have to be the control group that does not get that research. I am not a scientist; I know the member for Cottesloe is. That is part of the research. Are those people going to be denied other treatments? Will we have a group of people who are moved off less effective but still potentially effective treatment and placed in a control group in which they do not receive the known treatment and do not actually get the benefit of research but are the placebo group, and that is going to be done without their consent? Again, if the government were to look at improving this, maybe that is one thing it could think about. For the vast majority of people, it would be able to get some form of consent by using the framework that is spelt out in proposed section 110ZR. The government will apply proposed section 110ZS to a group of people for whom the placebo treatment is not appropriate—full stop; period. Let the other ones, the consent ones, deal with the placebo stuff. As I said when the minister was behind the Chair, there is a risk that a person subject to the research who is placed in the placebo group will receive no treatment or does not receive the other treatment that has been eschewed in favour of the research. Again, I think that stuff can be fixed. That is just some of the stuff that I was able to sit down and think about in the few minutes that I was listening to the second reading speech. This is a critically important area. Make no mistake, the Liberal Party, the opposition in this place, supports medical research 100 per cent.

Mr R.H. Cook interjected.

Mr P.A. KATSAMBANIS: Do not say that, minister; we do.

Mr R.H. Cook: I did not say anything.

Mr P.A. KATSAMBANIS: We have a strong history of supporting medical research, and particularly our local medical researchers. It is disappointing that too many researchers have had to leave Western Australia or Australia. We want them to access the best possible research here, but we must strike the right balance, and that balance is about protecting the most vulnerable people in our society who have no voice and no capacity to say yes or no to medical research. Unfortunately, we are being asked to make that decision in haste without appropriate consultation and without feedback from some stakeholders and the broader community. We are being told not to worry and that it will all be okay. We are not saying no; we are saying, "Bring in that part of the legislation that will apply to 95 or 98 per cent of people. Do it." The statutory review told us to do it. The Barnett government did not do it and the Gallop government did not do it either for three years or more. I know that the Attorney General has spoken about bringing in a broader package of reforms around a guardianship and administration bill, but he has only spoken about it.

We are not standing in the way and we do not want anyone out there to paint us as standing in the way. We are trying to find a balance between appropriate medical research and upholding the rights and interests of the most vulnerable, ill people in our society. To do that in 10 minutes in this place does not do justice for either those people or, unfortunately, our medical researchers. We know how some people opposite operate. They turn these things into a political football. They will think we are blockers or haters or whatever. We are not. That could not be further from the truth but the Labor Party's media machine will go into overdrive and spin, spin, spin. The most vulnerable people in our society are not political footballs; they have rights. If we start trampling on their rights, we may as well pack it in and give the game away. If we do not protect those people, who will we protect in this place? Yes, those people should be given an opportunity to access experimental research and experimental treatments. Everyone should. But when it comes to a lack of consent, we have to put more rigour around it. That rigour does not happen in the period between the minister sitting down after reading the second reading speech and me standing to reply. It happens with full transparency and with proper public consultation. It happens when the broader public, including the affected stakeholders, get an opportunity to have a say about it. It does not happen in haste and in a rush. That is especially the case when the experts such as Professor Fatovich and the like have told us that this will have some implications around COVID-19. We accept that, but the broader implications of this bill will be in ongoing medical research and in a host of other areas, some of which we do not know about today. It is imperative that we get it right from the outset because if we get it wrong, who will be harmed? It will be those vulnerable, incapacitated, ill people who have no voice and have no say and whose family has been shoved to one side and not consulted. Yes, the family might jump in afterwards and say yes or no, or whatever the case may be. However, as the minister said in the second reading speech, sometimes that might well be too late. It should never be too late for those sorts of people.

We are not opposing the legislation; we are simply pointing out the failure to consult, the failure of the process and the difficulty of having to make decisions about these critically important issues in such haste. I implore the minister to think about it. Ninety-nine per cent of what the minister is aiming to achieve can be achieved seamlessly today. We can pull out the other part and work on it. We can even work on it during this period if the minister so desires, but do not let the perfect get in the way of the good here. None of us should do that. I will not stand in the way of that. At the end of the day, we are in extraordinary and difficult times. We want people to be offered the

hope of receiving treatment and a cure from a horrific disease. We have seen the videos from around the world of people suffering and we have seen the harrowing statistics. We have done a great job here. The minister, the Premier and the government deserve credit for that. I give them that credit. We give them that credit. But on the margins, almost on a tangent to COVID-19, is the very tiny group of COVID-19 patients who may not have the capacity or any next of kin to give consent to urgent medical research. How big is that group? Does that group even exist? The latest figures show that only a handful of people here are in intensive care.

Mr R.H. Cook: It is 15.

Mr P.A. KATSAMBANIS: How many of those 15 do not have next of kin readily available to make a medical decision on their behalf? The minister may not know that answer. I certainly do not.

Mr R.H. Cook: I assume your question is rhetorical.

Mr P.A. KATSAMBANIS: It is, but it makes the point that we will end up fighting over the perfect when the good—proposed section 110ZR and all the good that will come from that—can be agreed to by everyone in a hurry. It is not that we disagree with the rest. I certainly am not. We are not opposing what the minister is proposing. We are simply saying that in this radically different new era a statutory report is sitting on the table that says not to do this, yet the bill is saying to do it, and we have been asked to make a decision on it in 24 hours. That is tough and unfair. I will leave it at that because I think I have covered a lot of ground.

I am grateful and thankful to the ministers involved for making their staff and public servants available and for sourcing professors to brief us on this. We have come a radically long way in two days. As I said, the bill before us today is vastly improved from the one I saw on Monday evening, and that is a credit to all the people involved. We are all rolling up our sleeves and working as hard as we can to get the right legislation through this place to protect the public of Western Australia, but perhaps in this case we should get the good and agreeable parts through here and then rethink the bits that perhaps need a bit more work done on them.

MRS L.M. HARVEY (Scarborough — Leader of the Opposition) [2.00 pm]: I rise to make a few brief remarks on the Guardianship and Administration Amendment (Medical Research) Bill 2020. First of all, we find ourselves in most unusual circumstances. Indeed, we are debating this legislation with a somewhat truncated program for consideration, which is why the opposition is raising these concerns. Ordinarily, legislation like this would be introduced and then there would be a period of around three or so weeks, and potentially more, for the opposition to consult the various groups that might be impacted or affected by it. We would then have time to go through the bill clause by clause and really understand how the legislation would operate, how it would impact individuals to whom it applies and, indeed, what the overall benefit to society would be from the introduction of legislation such as this. However, this legislation has been brought into Parliament in a somewhat rushed fashion because of the COVID-19 circumstances in which we find ourselves.

The opposition understands that treatments are currently being trialled on COVID-19 patients who have been suffering with pneumonia for a long time. Many patients around the world are losing their lives as a result of this particular form of coronavirus. I understand that different treatments are being trialled. Some of these treatments involve concoctions of antiviral medications that have been used very successfully to treat patients with HIV, who now have a life expectancy after diagnosis perhaps into their 90s as a result of achievements in medical research. I understand that these drugs are being combined and used with various effect on patients around the world to try to get a good outcome for them and to save lives. These are the circumstances in which we find ourselves in bringing forward the Guardianship and Administration Amendment (Medical Research) Bill.

I place on the record my appreciation for the medical research fraternity in Australia and the great work they do. As many people in this place know, I have had the personal experience of losing a loved one to one of the types of cancer for which the survival rate has virtually not moved over the last 40 years. Five years ago, pancreatic cancer had a five-year survival rate of around five per cent. The five-year survival rate is the number of people who were diagnosed with the cancer and are still alive after five years. It does not mean that the cancer will not necessarily take their lives; it means that they are alive after five years. Only five per cent of people diagnosed with this type of cancer back in 2011 fell into that category. Now, the five-year survival rate for that particular cancer is 9.8 per cent. It has not shifted very far, but the reason it has shifted from five per cent to 9.8 per cent of people being alive five years post-diagnosis is medical and clinical research trials of different drugs on patients around the world. Clinical trials look at how new drugs can be effective in treating people with that disease, which is why medical trials are so incredibly important. I have been a supporter of the Australasian Gastro-Intestinal Trials Group for a number of years and am also a supporter of the GI Cancer Institute and the Harry Perkins Institute of Medical Research in Western Australia. We can look at some of the statistics for gastrointestinal cancer. For those diagnosed with stage 1 stomach cancer, 65 per cent can expect to be alive after five years. Sadly, if someone is diagnosed with stage 4 stomach cancer, there is no five-year survival rate for those patients—none. For stage 3 stomach cancer, 25 per cent of patients can expect to be alive after five years. That is why clinical trials are so incredibly important.

During the time my late husband was being treated, his treating oncologist told us of what at the time was considered to be a miracle drug. He was treating a woman who had a very rare form of cancer—a gastrointestinal stromal tumour. She had weeks to live. She had been in treatment for a long time. All of a sudden, a clinical trial in the United States had success with a drug called Imatinib—excuse my pronunciation; I probably got that completely wrong. As soon as the success of that drug that was being trialled on patients in the US became known, the clinical trials diaspora around the world—all those clinicians involved in clinical trials—managed to make that drug available to the patient in Western Australia within 72 hours, and it saved her life. The efficacy of the drug had not been proven—it had had limited success—but she had three weeks to live and everything else had failed. She trialled that drug and it saved her life. Those are the sorts of circumstances that we need to cover in some way, shape or form with this guardianship legislation. The oncologist was telling me that every patient who suffers with cancer or a chronic illness dreams of a miracle cure like that. However, miracle cures come only from a commitment to medical research efforts around the world and from the medical fraternity in every country of the world having strong communication and interaction—through Europe, Australia, the USA, New Zealand and Asia. Indeed, China has certainly been involved in the development of various drugs and clinical trials for the treatment of COVID-19 in recent months.

I think the concerning point for members and why it has been difficult for us to contemplate rushing this legislation through the normal processes is that, as I understand it, the bill allows for a third party, potentially unknown to a patient, to make a decision on whether a patient can be part of a clinical trial and be administered with either a drug or a placebo. The patient might have a cognitive or other impairment or be otherwise unable to give informed consent to be engaged in a clinical trial, so that decision would effectively be made for them. The trap, if we like, is to be stuck considering whether it is in a patient's best interest to be administered with a placebo in that sort of environment, but I think we have to remember that we are dealing with patients who may be very, very unwell. Either option—being administered with an experimental drug or a placebo as part of a clinical trial—may shorten or lengthen that patient's life. Some clinical trials are in fact catastrophic for patients, in that they may have an allergy to the drug or the drug may not work in the way that clinicians or researchers anticipated. However, we need to understand that usually these are very sick people for whom medicine has no answer or solution for their medical condition.

Medical trials become one of the areas that people look at when the end of their life is rushing towards them. It is then that they often want to be part of clinical trials. Some people may have wanted to be part of a clinical trial but may have reached a point at which they cannot give informed consent because of the symptoms of their disease, even though it may be understood that they would have wanted to be part of a trial. I implore the minister to find a way to expand the use of advance health directives to have more people fill them in and indicate whether they would choose to be part of a clinical trial that might reverse their conditions or improve their symptoms should they indeed reach cognitive impairment. It is far better to make those decisions when one is conscious and has full cognitive capacity than to have, as this legislation will enable, a third party who may not even be a family member make a decision on one's behalf. Sadly, broadly in our community, a large number of people do not have very mature conversations around death. The panic that we have seen in the community over the last few months around COVID-19 is indeed indicative of the lack of mature conversation around death and our own mortality. Death is the one thing we all have in common. At some point our lives will end and contemplating that is difficult for the vast majority of people, as evidenced by the very small number of people in the population who take up advance health directives and put in place documents such as enduring powers of attorney, enduring powers of guardianship and a last will and testament.

We find ourselves with an interesting set of circumstances. It is certainly very worrying for a lot of members to rush through legislation like this, but in the interests of the bipartisanship that we have offered to the government in the COVID-19 scenario that we find ourselves in, we have been negotiating furiously with it to try to get some checks and balances on some components of the bill that we are uncomfortable with to put members' minds at ease. I have a copy of a letter from the Public Advocate to the Attorney General, John Quigley, on this bill. I will read from this letter, because it is important for the house to be aware of it —

> Both my office and the Department of Health, specifically requested medical research be considered in the Terms of Reference of the review, as it has been an ongoing issue for guardians and there is a lack of clarity in the Act.
>
> I met with Professor Gary Geelhoed, Executive Director, Western Australian Health Translation Network, on 18 June 2018 who addressed the concerns I raised in the Statutory Review regarding the provision of placebos in medical research. I was assured that, should a person receive a placebo during medical research, they would still receive the best possible existing treatment for their condition, they would just not receive the novel treatment being trialled in the research. I understand placebos to be an important part of medical research, and am confident that, should a person receive a placebo during medical research, they will still be receiving the best available treatment for their condition.
>
> I am supportive of the amendments in the Bill which will enable myself, as the Public Advocate, to consent to medical research on behalf of a represented person, where that research is in the person's best interests

> and will have no detrimental impact on the person. I note that the assessment by an independent medical practitioner of the research candidate's best interests provides a key safeguard which assist guardians and other research decision-makers in making their decision about the participation of a represented person in medical research.
>
> I have viewed all drafts of the Bill as it has developed, and am confident that the Bill ensures that the best interests of the person remain central in the amendments. As is required in the Guardianship and Administration Act 1990, the amendments ensure that all medical research decisions are made in the best interests of the person, and regard the wishes of the person as the paramount consideration.

That letter from the Public Advocate to the Attorney General has indeed put to rest some of the concerns that I held about people without the capacity to make decisions for their own welfare being considered. I know and have a great deal of respect for the Public Advocate, and I know that she would not have penned a letter like that unless she had absolutely assured herself that those people who are the most vulnerable in our medical system, those people without the capacity to consent or make decisions, will be regarded properly as part of the medical research component of this legislation that will allow them to participate in clinical trials, albeit without signing up to them consciously.

I would also like to put on the record my appreciation to a number of public servants who have been frantically drafting and redrafting this bill, looking at opportunities to make amendments, take on board some of the views of the opposition and look to things such as review clauses. I was very heartened to see the Minister for Health agree to having the Education and Health Standing Committee of the Legislative Assembly oversee a review of this legislation within a very short time after its introduction. I am very pleased with that development, because once we get through the set of circumstances that we find ourselves in, I think many members in this place from every party would welcome the opportunity to understand exactly what this legislation is intended to do, to determine whether there may be unintended consequences and give it proper consideration.

Excuse me; I am going to be coughing now, and everyone is going to desert the chamber!

The ACTING SPEAKER (Ms J.M. Freeman): There is some hand sanitiser just there.

Mrs L.M. HARVEY: I am not contagious; I just have a tickle in my throat.

Given that my voice box has now determined that it is time for me to conclude my remarks, I would just like to encourage the minister to continue working with all members to ensure that we get this legislation right, with the protections we need to put at ease the concerns of members around the areas that have been raised. I put on the record that I considered the inclusion of a sunset clause, but I would not like to see a sunset clause included that would interrupt very important medical research trials and perhaps halt them. I would not like to see that scenario, because it is only through clinical trials that we start to get breakthroughs in medicine, and it is only through those breakthroughs in medicine that there is an opportunity to save people's lives. Obviously, of particular concern and interest to me is to see a breakthrough in gastrointestinal trials and research in that area. We need to see the outcomes for people with these horrible diseases, cancers and diseases such as Alzheimer's, for example. We need clinical trials to get results and to get outcomes to save people's lives. I am a big supporter of the medical fraternity. I know every single person in medical research wants only to save the lives of people and improve outcomes for people with these diseases over time. This legislation indeed facilitates that research; I am happy to stand in this place and support it.

MR W.R. MARMION (Nedlands — Deputy Leader of the Opposition) [2.18 pm]: I would not normally speak on a bill that the government is trying to rush through, but I want to make a few comments on the Guardianship and Administration Amendment (Medical Research) Bill 2020 because it is a bill I would normally be quite interested in. My electorate of Nedlands has a lot of researchers, obviously at the Harry Perkin's Institute of Medical Research and the Telethon Kids Institute, where a lot of world-leading research is taking place. I am concerned that this legislation is so rushed. I picked up the bill as the minister was reading his second reading speech, and I have not had a chance to read it. I feel quite vulnerable talking on a bill I have not even read. I learnt how to use Zoom on my phone at quarter past 10, and I had some problems, because I put it on my phone and the briefing was for over an hour.

Mr P.A. Katsambanis: You'd better clarify whether it was the zoom on your phone or the Zoom app.

Mr W.R. MARMION: It was the Zoom app, for the purpose of *Hansard*.

I thank the minister for the briefing. Professor Daniel Fatovich was outstanding. I could not fault his explanation on research, but I did not have questions about research. We spent about an hour on research and placebos and my colleague from Cottesloe and I have an in-depth understanding of how that works. I wanted to know a bit more about what the bill is for and the continuum between someone being sick and when they participate in a trial. I thank everyone who participated in the Zoom meeting. I also absolutely congratulate the Solicitor-General. I was all over the place with proposed sections 110ZR, 110ZS and 110ZT because I did not have a copy of the bill during the briefing. I had to write things down. The Solicitor-General was good in the way that he explained things. He has a very good mind. Thank goodness he made it fairly clear because now I understand that proposed section 110ZS

will be the non-traditional decision-making section of the act and that proposed section 110ZR will be the traditional decision-making section. No-one has problems with traditional consent for trials. However, there is concern about non-traditional consent. I must congratulate the member for Hillarys because he covered all the points that I want to make. I will embellish a couple of the points that he made. I have no problem with proposed section 110ZR, but we would have liked more notice to contemplate the amendments. Sometimes we need a few days to understand what something is before we see its merits. It is very hard to receive a bill at 11 o'clock and talk about it at 2.30 in the afternoon on the same day and say whether or not it has our support.

As some members in this place know, I lived in Wittenoom. State governments rarely fund research, but the state government funded a vitamin A trial in the late 1980s and early 1990s and because I was a Wittenoom resident, I was able to participate in the trial. I was not a very good participant. I do not know whether I had the placebo tablet or the vitamin A tablet. There were two trials—one was for those people who lived in Wittenoom and one involved a stronger type of vitamin A for those who went down the mines. My father was on the trial.

Mrs L.M. Harvey: You're still here, Bill!

Mr W.R. MARMION: I am still here! It was interesting because, as it turned out, they found that those who were given the placebo were better off than those who were not given the placebo. Professor Fatovich made the point that sometimes people are better off on the placebo. In terms of developing cancer, those given the placebo are marginally better off. I was not very good at taking the tablets.

Mr P.A. Katsambanis: I had to take a whole pile for two years.

Mr W.R. MARMION: The tablets were about this big and were very hard to swallow.

In fairness, in the trial that involved a different type of vitamin A—the stronger variety for those who went down the mine—there was a marginal effect. Unfortunately, most of those people have passed away. It probably slowed down the disease a tiny bit.

I have deviated. I saw mesothelioma patients when they were diagnosed and had only six to 12 months to live. Professor Bruce Robinson ran a trial at Charlies. I met patients who were using interferon. As a patient—or as someone's spouse or guardian—I would be concerned if I were placed on the placebo. I was pretty sure that Professor Bruce Robinson gave people the actual interferon medication. Before someone can consent to a regimented clinical trial, is there an opportunity for a patient—a customer, if you like—to consent to a drug, not a trial? I understand how clinical trials work and that there has to be a placebo; otherwise, it is not a clinical trial.

Mr R.H. Cook: A control group.

Mr W.R. MARMION: A control group. I understand that. I know that people cannot tell whether they are on the placebo. Double blinds are used so that even the doctors and researchers do not know what patients are given, because if one of their relatives participated in the trial, they would probably want to slip them the real drug, not the placebo. I understand that they have covered all of that. The professor did not go into that in depth, but I understand how trials work. I would be quite happy to take the drug. If someone told me that I had mesothelioma and that I had six months to live, I would rather not go on a trial. I would prefer to have the drug: "Give me the drug and see how I go." I am interested in the minister's comments on that. If I was conscious, I could say that. If a relative was not conscious and I had to make that call as their guardian, I would make the same call. It would be the last resort to agree to put a relative on a clinical trial knowing that my loved one, if I were their next of kin, could be given a placebo.

During the briefing via Zoom, the Solicitor-General mentioned two policy questions that we as policymakers in this house have to consider. The first was whether the decision should be extended to the non-traditional decision-maker, so should a researcher and an independent medical practitioner make the call? Should that policy be made? The member for Hillarys made the point that a report, which I have not read, recommended that we do not go that far. That is obviously a consideration. The government has made the call that this is what it is going to do. The second policy question that the Solicitor-General addressed was around placebos. If a person is going to participate in a clinical trial, they cannot debate the policy around that, but the policy is really about whether someone who is sick and dying should be given medicine or whether they should participate in a clinical trial in which they could get a placebo. The Solicitor-General said that he needed direction on those two policy questions before he could make comment. That is where we should focus our attention.

Another point that the member for Hillarys made is that we are here in this house because of COVID-19 measures. The temporary orders state that the house will undertake immediate business arising from COVID-19. There is a suggestion that the measures in this bill extend further than COVID-19 because they are not just about COVID-19. Obviously, COVID-19 research is absolutely fundamentally important. It is going on all around the world and it would be great if we could participate in that. Obviously, we can participate if guardians make the call for patients who cannot make that call. I do not think the number of such patients is large; I think the member for

Hillarys asked that question. I do not know what impact this legislation will have on COVID-19 in Western Australia. I think a minimal number of customers, patients or people would not be in a position to make a decision and would not have a guardian to make that call. I am sure that in other countries it may be more significant.

I want to highlight that it is very unusual to have to talk on a bill that we have not read. That is of concern to me and I am, maybe, not the only person who has that concern. Normally, I would rely on my colleagues and be sure that they have read it, but even my learned colleague the member for Hillarys has just told the house that he would like more time to consider it. I am relying on the member for Hillarys to have had a better look at it than I have. I am hoping that, if there are problems with it, the minister will look at it carefully and, if problems arise, the government will deal with them as soon as possible.

DR D.J. HONEY (Cottesloe) [2.30 pm]: When we consider the Guardianship and Administration Amendment (Medical Research) Bill 2020, it is very clear that it is being put forward in the context of the coronavirus crisis that is afflicting the world and affecting our state. It is very clear after the "I move" part of the second reading speech. It states —

> The government of Western Australia has declared a state of emergency and a public health emergency in response to COVID-19 and severe changes have been rolled out across the community to assist in stopping the spread of COVID-19. The state government is acting on the best medical advice in the country, but as a government we can do more to help our medical community and those patients who are suffering in their fight against COVID-19.

When we are reviewing our response to the legislation now, we need to do that in the context of this legislation as it has been put to us—that is, in the context of the coronavirus crisis. Although we have a current emergency, which is all too apparent to anyone who, I think, is standing upright, the changes we are making now are, effectively, forever. Past the time of this crisis, this bill will persist. It is an interesting time. There has never been a time like this, I would say, for all of us in our lives, outside of a personal crisis. As a community, I do not think there has ever been a time when there has been a greater requirement for urgent action. But, equally, in that time there has never been a time when we need to proceed with greater caution. Those two things sometimes seem contradictory. In this place, I think we are demonstrating that, hopefully, we can balance those two key concerns. Old proverbs can sometimes shine a light on current dilemmas. A saying attributed to Mohammed is: "Paradise is surrounded by hardships and the fire is surrounded by desires." As the Minister for Mines and Petroleum would know, another variant of that proverb is that the road to hell is paved with good intentions. I am not for one moment contending that this bill is a path to hell, but I am concerned that part of the bill could have an undesirable consequence. I have no doubt whatsoever about the minister's genuine intent in supporting this bill and that it is critically important. I have no doubt at all that Professor Fatovich, who was one of the experts in the briefings we had, was very genuine in the reasons for supporting this bill. However, it is not unusual in this place for us to have concerns about a bill that is strongly supported by reputable and well-meaning people. I think we saw that illustrated to great length when dealing with the Voluntary Assisted Dying Bill 2019. There were very good people and very good intent on both sides of the debate, but, equally, there was a strong disagreement about some parts of it.

As has been made clear by our leader and the previous speakers on our side, I, like the rest of my colleagues, support the overall intent of this bill. It is very clear in the current crisis that this new terrible disease that is facing our community and the world will require new treatments. From the state's point of view, we have a fortune from others' misfortune; that is, we are not the first in the world to be afflicted by this, so we have an advantage over other countries in which it is more advanced. Treatments are emerging for this disease, either to prevent people getting infected with a vaccine, or to mitigate the impact through the application of medicines.

When we are looking at this bill, I am concerned that we are considering quite significant changes to the guardianship laws in this crisis period and in an air of crisis. I understand the justification being given, but I am concerned that certain parts will have long-lasting undesirable impacts. I have not had the chance to review this bill before today. Importantly, I have not had the opportunity, outside the briefing on Monday and today, to have input and discussion needed to review the bill. That has me concerned. In this climate and given what we are looking at, I am not sure we should make permanent controversial decisions. If there are parts of this bill that are controversial, I think that we should have a mechanism that can allow us to deal with the crisis at the moment, but will allow us to review those things in a more considered way at a later time.

The justification for dealing with this bill is the COVID-19 crisis. To focus my comments, I am especially concerned, as are other speakers, about a person being able to be subject to a novel or experimental treatment beyond the scope given in proposed sections 110ZQ and 110ZR and the associated sections around the substitute decision-maker for a research candidate.

If we look at those proposed sections, I think most people, and certainly every member on our side who I have heard speak on this matter, see that as reasonable; that is, someone who is reasonably close to a person can, in an urgent

situation, make a decision on behalf of that person. That is something that people see as being reasonable and something that, in the current circumstances, could help people with novel treatments. I am concerned that there has not been proper time to consult on proposed section 110ZS, which is urgent medical research without consent. There has already been some discussion of that. Some members here would be aware that for urgent decisions there is an existing mechanism to achieve outcomes through the State Administrative Tribunal. If we allow a person who is an intimate relative of someone to make a decision, which we have all said we support in this legislation, that will substantially expand the scope of experimental or novel treatment on people who could be affected. I suspect that is going to be 95 per cent of the people or some such number. But we already have the mechanism of an application to the State Administrative Tribunal, and the Public Advocate being able to make that decision as a substitute intimate associate of the person who is being treated.

As an aside, and I am sure that clever minds have looked at it, perhaps it is worthwhile to look to see whether that mechanism can be streamlined. I understand the contention that sometimes these decisions have to be made very urgently. I will not go through the logic of that here. I think, perhaps, that has been overstated a little. Typically, in the most urgent situations, in the community, at least, it is dealt with by first responders and they certainly will not use any novel treatments. They will apply standard emergency first aid to preserve someone's life until they can get to a hospital. I am sure that people could work out a mechanism to make that currently available mechanism more streamlined if it were needed during this crisis. I am certain that members of the State Administrative Tribunal, like the minister and other people here, would be prepared to put in the extra time to do that. I could accept a time-bound clause of the nature of proposed section 110ZS. It has been put in the context of the COVID-19 crisis and that we could focus it on this crisis. That is something that has been discussed. Our leader has already discussed concerns around the effect on clinical trials. I will say more about that a little later.

During the briefings on this bill, it became clear that a treatment in this context can comprise a placebo. I found that surprising. The primary justification for this bill relates to a person suffering from COVID-19 who is unable to give their consent to avail themselves of a treatment that could save their life, or improve their quality of life, and that we need the capacity for that treatment to be delivered to them even when an intimate relative cannot be contacted. I will be direct and say it is nonsense to say that being able to apply a placebo in that context makes any sense whatsoever. I heard the discussion today about placebos. Placebos can have a real effect in conscious people. A large study published a number of years ago indicated that the placebo effect for all drugs can be up to 50 per cent. Over a cohort of studies, it was about 50 per cent. That is for people who were aware they were being treated.

We heard in today's briefing that maybe a placebo could unconsciously affect medical research, but I will again be direct: for an unconscious person—a person who does not have the capacity to give consent—I suspect that that is a very minor effect. If a patient who had COVID-19 were being treated with something that would make them better, I do not think that a placebo could be considered in that context. My community test on this would be to go to the relatives and ask whether they support this treatment if they are going to be given something that good people think could save their life or improve their life. I suspect most relatives, post the event, would say, "Yes, absolutely, you did the right thing; that's the thing I would have done." But if the relatives were told, "Yes, we had to intervene in this way but we gave your relative a placebo", most would be pretty angry. In fact, they would say, "Hang on, you're doing this under some emergency power but you're actually not really giving them anything that can improve their quality of life." I will not labour the point. That does not make sense in the context of responding to the COVID-19 crisis.

Today, we had a further briefing from the State Solicitor and Professor Daniel Fatovich. Like previous speakers, I am extremely grateful for those briefings. As the member for Nedlands alluded to, the State Solicitor was patient and kind in his responses. It was very good to have someone of the calibre of Professor Fatovich to give the responses. It was very clear that Professor Fatovich is a compassionate and caring person. Out of anything that is said here, that would be a shared view of members, and nothing that is said here contradicts that. It was also clear that he was very much looking at the legislation as someone who was an active researcher; someone who is interested in the research process. When we were going through those reviews, I asked Professor Fatovich two key questions in relation to justifying the critical research need embodied in proposed section 110ZS. What critical research was driving it? One question was: in a medical trial, what percentage of patients in a critical care situation require novel treatment? Professor Fatovich could not give me an answer. I was not trying to trick him. I did not expect him to have an estimate. I did not think he would have a number; I thought perhaps he would have an idea. The other question was: in what percentage of cases was the clinician unable to obtain consent for a novel treatment? Professor Fatovich did not know. Again, I am not in any sense whatsoever implying criticism of him. The reason those two questions are important is that they define the size of the issue we are talking about. My suspicion is that both those percentages are quite low.

I made this comment during the briefing: clinical research is very rarely 100 per cent one way and zero per cent the other way. By its nature, given the variabilities of humans and diseases and the like, it is usually a balance of probability. Looking at this from a clinical research perspective, I do not think there is a strong argument to justify

proposed section 110ZS. I could understand a stronger argument from the point of view of actually giving someone a real medicine that they think will help that person, but not from a clinical research perspective. I am not satisfied about excluding that small cohort of people who are in critical care and require the novel treatment when there has been no ability to collect approval from a person intimately connected with that patient. I am not at all convinced that that will fatally injure any research program. I would be very surprised if that were the case.

I am concerned in that context that the justification for proposed section 110ZS, from a clinical research perspective, is somewhat overstated. As I mentioned, I would be more relaxed about proposed section 110ZS if it contained a sunset clause. I appreciate exactly the point my leader made, and that is the complexity of continuing trials. I will say, though, in terms of continuing trials, I would be surprised if it were not possible to get some informed consent for people who were already being treated in a trial scenario. If there were a sunset clause, I am certain we could have some mechanism. In fact, I am certain that in the majority of cases relatives would be contacted and their approval could be gained for them to continue in that trial, recognising if a close relative subsequently decides they do not want the patient to be in the trial, I assume, given the other clauses in the bill, that permission to be in the trial would be withdrawn in any case. I do not think it is as big a problem as has been painted in terms of people continuing in that trial. I think there would be plenty of time to get that consent in any case and they would end up with an even smaller subset.

[Member's time extended.]

Dr D.J. HONEY: In the last briefing, the State Solicitor very succinctly distilled the key concerns about the bill. I hasten to add that they were not his concerns; he was simply trying to summarise the concerns of some of the members who were participating. One concern was: should the clinical decision be extended to researchers? The subparts of that were: Could that particular decision be refined by topic or time? Could the government limit this to COVID-19, understanding that people have put broader arguments, and also could this be dealt with by regulation? I assume that the State Solicitor had a thought in his head that regulation could deal with this. The second key concern was: is there any justification to allow the administration of a placebo to an incapacitated person?

I say in conclusion that I am very grateful and thankful for the way the minister made his staff and others available for the briefings. I also welcome the offer the minister has made to refer this bill to a committee. That would allow for some deeper consideration of this bill. I hope that that committee will take note of my concerns.

MR Z.R.F. KIRKUP (Dawesville) [2.49 pm]: I, too, rise to join my colleagues speaking to the Guardianship and Administration Amendment (Medical Research) Bill 2020. At the outset, I endorse the comments made by a number of my colleagues thus far, particularly the Leader of the Opposition, noting that we meet in extraordinary times. Obviously, a number of extraordinary pieces of legislation have been introduced in this house for us to consider in a relatively short period. The members for Hillarys and Cottesloe and the Leader of the Opposition outlined their concerns, especially about the expeditious approach that has to be taken to move the legislation from the Legislative Assembly to the Legislative Council and then obviously go on to become law. It is a considerable task.

At the outset, I express my disappointment about the comments made by the Premier who suggested that somehow we were not cooperating. In the area for which I am responsible, with the cooperation of members in this place, and the party more generally speaking, we have been working very hard to try to meet this government's ambition to pass extraordinary legislation. I would be surprised and happy to call out any member, government or otherwise. We have been negotiating with the government consistently, very openly and in good faith. I think we have done an extraordinary job, which is to the credit of the Nationals WA and the Liberal Party, which continue to step up when called upon. It was a disappointing contribution, as evidenced by the fact that a number of members who were outside kicked up during an otherwise relatively sombre, toned and pared-back question time.

The health response to COVID-19 is the reason we have been called to this place. It is the nature of the temporary order under which we now meet. We are obviously here to respond to COVID-19 and the crisis it presents to our state and its residents. At the outset, I take the opportunity to continue to thank our healthcare workers, wherever they may be, who are doing an outstanding job dedicating their lives to fighting COVID-19. The clinical response has been exceptional. A response has also been put together by the public service. We have seen an impressive reorientation of the public sector when required, which we fully support. The Minister for Health has updated the house and the public a number of times, saying that the public sector is moving largely towards contact tracing and other mechanisms to help fight COVID-19. That shows the fight that is occurring; we are all in it. The Minister for Health already used language such as this being about "Team WA". In this chamber, in this Parliament, across the public sector and, indeed, across the broader community, we are all in this fight together. We have seen an impressive response from Health. We have discussed this with the minister in private, but some people have knocked the department and its team for its responses. I do not think they can be questioned. The Department of

Health, our hospital workers and our health workers are all coming together to respond in exceptional circumstances and are doing an amazing job. I thank them.

When I wrote my speech, I was going to talk about the lack of a COVID-19 clinic in Mandurah. I was pleased to hear during question time that the minister addressed that for me and we can look forward to one being established in Halls Head in the not-too-distant future.

Mr R.H. Cook: I'm glad I headed that off at the pass!

Mr Z.R.F. KIRKUP: Indeed. That is an outstanding result and one that we welcome. I look forward to that being done hopefully very soon, once the facility is properly bedded down.

While I am on Mandurah, Madam Acting Speaker (Ms J.M. Freeman), if you can indulge me for a moment, as of this morning, more than 718 volunteers from across the community stood up and said that they want to help respond to COVID-19 and the impacts that it is having on vulnerable people and the elderly in our community. I would like to thank the hundreds of volunteers who have come forward. It is an exceptional result. It shows how much we are all in this together. Mandurah is hurting, as is Perth, the state and the country. At times like this, we see the good people get better and the bad people get worse. I have seen nothing but the good and the great in Mandurah coming together. I thank in particular the team in my office. On Tuesday alone, we received more than 400 emails in an eight-hour period and a number of calls. I had 100-odd calls on my mobile. Every time there is a significant shift in government policy, everyone wants to find out what is going on. We get more information. This could not occur without the local effort to help coordinate some of the responses from the vulnerable in my community; it could not be done without the team in my office, who I am incredibly grateful for—Amanda and Gaynar—and the volunteers who have come in. They are doing a great job.

I heard the Premier on the radio today—I think it was ABC radio—saying that I am participating in a fundraiser with the Australian Medical Association and the Liberal candidate for Kingsley. I find that disappointing because it is not a fundraiser at all; it is a community grouping that will be held via teleconference. I found it disappointing that the Premier would seek to politicise that when all we are trying to do is provide information that is not partisan in any way, shape or form. It has been done with a candidate who is standing in that community who wants to make sure that the community is as best informed as possible. I was disappointed to hear the Premier say that we are fundraising on behalf of the Liberal Party together with the AMA president, Dr Andrew Miller. That is not the case. We are simply making sure that the good people of Kingsley have access to more information via a teleconference. I do not see any problem with that, especially if it is just straightforward information that people want. I do not understand the issue and I do not understand why the Premier does not want people to have more information. I am curious as to why he sought to suggest that it was a fundraiser. It is not the case. We will ensure that people are well informed at every point. That is all members of Parliament are doing. Everyone across the community will help their mates, their friends and family and provide information. We are just doing it by way of a teleconference. That is a good thing. It will be held on Zoom.

Before I get to the bill, I wish to talk about COVID-19 a little because that is the reason we have been called to this place. Part of the legislation that we are seeking to pass today deals with the COVID-19 response. I find the issue of COVID-19 quite fascinating. From the level of energy that it has taken to the time and effort put in to ensuring we stay across this issue is akin to more than the effort that we put into the voluntary assisted dying legislation and the amount of work that was done in that space. I am only in the opposition. We are doing work to try to make sure that we keep abreast of the changing times; things seem to change on an almost half-hourly basis. We are making sure that our colleagues are as best informed as possible, talking with stakeholders and liaising with the community whilst preparing for the negotiations of this sitting. People have done a lot of work. We are trending in the right direction in Western Australia, in part to the good work of the state and federal governments with the measures they have taken thus far, which we support. Ultimately, we want the government to succeed. If the government does very well, the people of Western Australia do well. That is absolutely where our heart is as an opposition. There is no opposition to the measures that have been taken so far. Of course we will want to find out more information. We want to ensure that we talk on a regular basis. I appreciate the fact that the Minister for Health is consistently very accessible. I have found the relationship between his team and I to be second to none, to be perfectly frank. At no point has there been an issue on which I could not talk to the minister, his chief of staff or his team. I am very thankful for that. It has been a bit instructive to me how I would seek to operate as a minister—working cooperatively with members of Parliament, particularly the opposition, during times like this. I thank the minister for that.

At the moment we have 392 confirmed cases of patients with COVID-19 in Western Australia. A large majority—I think more than 85 per cent—are in some way directly linked to travel of some sort, whether it is international, interstate or cruise related. The numbers are good but we cannot afford to be complacent at this point. I am really worried that people may expect that we will get the rate down and we will be done. That is not the case. We have

to be prepared for the fact that we will be in this situation for months; I think for longer than six months, personally. None of us have a crystal ball. There is a real concern that this situation will be done and dusted soon. COVID-19 will be with us for some time, which is why we will not stand in the way of any measures the government needs to take. We should take any measure we can to try to reduce the amount of time that COVID will have an impact on our society.

This morning, the member for Kalgoorlie was talking to me about the need to provide more information to Aboriginal communities in regional Western Australia, particularly in the goldfields. That is a real concern. All of us in this place understand that. I know that the government has been working very well with Aboriginal medical services to try to get more information out to Aboriginal communities in Western Australia.

There are still so many things that we do not know about COVID. The lack of certainty is causing a sense of anxiety that I entirely understand. I consistently get many questions from across the community. Friends and family want to know as much as they can about this. There is so much that we do not know. COVID is unlike any other virus we have seen, and everyone refers to the Spanish influenza pandemic in 1918 and 1919. I have said it before in this place, but I find the government's response to some of the COVID issues reminiscent of the then government's response in 1918 and 1919. We had significant issues with the Spanish flu, including with vessels offshore. I think Hal Colebatch closed the border of Western Australia in 1919. There was a drive to get more nurses. There was, of course, no vaccine. A lot of the issues that we were dealing with then were obviously happening in a different time, but they resonate today. The response from the government in trying to get all these pieces of legislation through is remarkable, so we have heeded that call in a quiet, agile and nimble fashion. The opposition has stood ready at every point to help the government pass these bills.

I encourage members, if they get the time, to try to understand more about this virus and perhaps why this bill is required. It is obviously a novel virus in terms of how it has been defined in the past. There are two aspects of this virus that I find interesting in terms of why it is so different and has had such an impact on humanity as we know it. The first is its composition. It seems to be perfectly designed to sit within, without using a scientific term, the ecosystem of the lungs. It is almost perfectly designed to sit within the cell structure of the lungs. Protein hooks attach themselves to the lining of the lung, and I think it uses the protein furin to inject a harpoon and fuse together with the lung and start to cause an inflammation. It is very, very hard once that process starts. We know that circa 80 per cent of people do not get more than mild symptoms, but a large number of people get very ill. I am really concerned about the attitude that young people are not getting it. That is not the case. Unfortunately, a number of young people are getting this virus. When I say "young", I mean those under the age of 35 years, so I can be included in that category. A number of young people are very ill as a result of COVID and the acquired pneumonia that occurs.

There are a lot of questions that we do not have answers to. We do not know how this virus started. We do not really know where it came from. One study that I read in *Nature* suggested that it came from the horseshoe bat, which is very small. As I have since learnt, bats act as the perfect reservoir for viruses. A virus does not want to kill a bat; it wants to get transferred. That is possibly where it came from, and possibly through the illegal mammal trade in China. We also do not know why COVID is so virulent and why it has had such an impact. I read a World Health Organization study last Friday that suggested that the likelihood of this being transferred by airborne means is probably less likely than it being transferred by droplets and through contact. Obviously, it has spread around the globe at a rapid rate. As of yesterday, more than 800 000 cases had been reported. I do not know the global figure today. Developed countries have been significantly impacted by this. I fear, as the Premier and the minister have said in this place, what will happen once it reaches Africa as it sweeps its way around the globe.

The reality is that it is not business as usual anymore; our daily lives have been impacted in a significant manner. It is important during these times that people know that they are not alone and that their Parliament and their elected representatives are doing all they can to respond to this. If one of the bills that needs to be passed is the Guardianship and Administration Amendment (Medical Research) Bill 2020 and the government genuinely believes that it will help with the response to the COVID epidemic, I will support it. A number of members in this place have raised concerns, and I understand and echo those concerns. The members for Hillarys, Cottesloe and Nedlands raised concerns, especially about consent and the intervention of clinicians. I genuinely believe that the government wants to work in a collaborative fashion, particularly in the upper house, to make sure that the concerns of the Liberal, National and other parties are heeded. I take it as a good sign that some changes have been made overnight. With the heightened sense of uncertainty that exists, the people of Western Australia expect us, as legislators, to do everything we can to respond to this by whatever means necessary at this time.

We have seen an exceptional curtailment of our usual liberties in daily life. We have seen border closures, regional travel bans and plenty of restrictions on shopping and where we can eat and drink. All these things have changed. It is an exceptional environment that deserves and, in this case, warrants some exceptional pieces of legislation. I mean that in the sense that it is, by and large, very abnormal to see this process that is taking place. As the member

for Hillarys has alluded to, in the past this bill would have warranted probably weeks of scrutiny in this place and in the Legislative Council. Unfortunately, that is not practical at this time. I appreciate the undertaking that the minister has given to the Leader of the Liberal Party that a parliamentary committee will oversee the review of this legislation and that some work will be undertaken with my colleagues in the other place to ensure that a lot of the other concerns are addressed.

There is a lot that we do not know about COVID-19. Any measure by any Parliament to help respond to this and enable, hopefully, better clinical outcomes is a good thing. Trials are being undertaken right now across the globe that could have a significant, beneficial impact on potential victims of COVID-19. I would hate Western Australia to be excluded from a trial that was operating elsewhere in the country and for our patients here not to have the legal capacity to participate in that trial for some reason. The members for Cottesloe, Hillarys and Nedlands have outlined the nuances in this place, and I support those concerns. I am hopeful and confident that the Minister for Health and his team will respond to those concerns and amend the bill as required in the upper house. Between now and that point, I hope this legislation goes some way in the fight against COVID. It is certainly one that I support.

MR P.J. RUNDLE (Roe) [3.08 pm]: I rise to speak on the Guardianship and Administration Amendment (Medical Research) Bill 2020. Firstly, I would like to recognise the work of the Minister for Health. He has done a great job in trying times. It is very much a time when we are all concerned. On behalf of the Nationals WA, I certainly thank the minister for his efforts during this time, as well as, of course, all our health workers and the people on the front line. Last night, I spoke about those on the front line who are helping our communities. It is really important that they are recognised, because it is a time when all our metropolitan and regional communities alike are worried. When I think about it, we are obviously going into uncertain times. I also believe that the minister has been leading from the front and certainly he has been keeping the community of Western Australia well and truly updated each day. People look forward to those updates. I thank the minister and all our frontline workers.

I would like to go back to Monday afternoon when I was on the farm at Katanning and received this bill 20 minutes before the briefing from the State Solicitor's Office was to commence. As members can imagine, it is a very comprehensive and important bill, in my view. I believe that it is potentially one of the most important bills in Western Australia for many years. From my perspective, it was quite a surprise when I saw this on the government's agenda. We very much understand the urgency for it. I suggest that, in some ways, this bill is almost more controversial than the Voluntary Assisted Dying Bill, which took many months to advance and was looked at from many angles by this chamber and the Legislative Council. Obviously, in a voluntary assisted dying scenario, people have the ability to make their own decisions. This bill is all about guardianship and people's ability, or lack thereof, to make decisions.

The bill has been kicking around since the 2015 statutory review and has been discussed between the legal and medical fraternities. It was on the books but it has suddenly come to fruition. We are in this trying time of COVID-19 but I am concerned about the way this bill has suddenly come through the ranks to be urgently tried and tested when we have not had the time to consider it. In some ways, I believe that is opportunistic. I understand the urgency for it but I believe this bill needs more scrutiny. Under normal circumstances we would have heard from many speakers in this chamber and had at least two or three days to debate the bill in the Legislative Assembly. I imagine that the bill would have gone to the Legislative Council and ended up in committee, which would have taken several months, followed by several days, if not weeks, of debate in the Legislative Council. That is the perspective I am looking at it from.

The Nationals WA certainly understand the bill's urgency and we will not oppose it. However, along the lines of some of the other bills that have come into the chamber in the last couple of days, we believe that a two-year sunset clause would be a good way to go. We know that treatment for COVID-19 is needed and that there are research and guardianship issues, but those issues could all play out over the next 12 months, allowing Parliament time next year to fully look at the bill in the way that it should be looked at. I understand the provisions in the bill and I spoke to my parents about them the other day. If they or I were on death's door, I would take up the opportunity to use new medical research that had developed a quinine-type drug that we have heard about, if it could save my life or my parents' life. It is important to make that point.

A two-year sunset clause similar to the 12-month sunset clauses in the Emergency Management Amendment (COVID-19 Response) Bill 2020 and the Criminal Code Amendment (COVID-19 Response) Bill 2020 would give COVID-19 the opportunity to play out. We could therefore take the necessary emergency measures, pass the legislation and deal with the measures contained in it over the next two years, in this case.

I refer to the modified standing orders. We are in Parliament with only a handful of members—six or eight—spread out across the chamber because of social distancing. I have heard concerns from other Nationals WA Assembly members who have said that they, along with me, have not had an opportunity to look at this bill. A couple of them came in late to a couple of Zoom videoconferences. They are worried about their ability to represent their constituents'

views. I do not think we have had an opportunity to consider the legislation in a meaningful way. I think I have a reasonable capacity but I cannot keep up with the drafts. When I sat on the verandah and listened to the first briefing on Monday afternoon, we were up to the fourteenth draft. I was informed that it had gone from the third draft to the fourteenth over four or five days, and now we are up to the twenty-first draft. That is my problem, but I do not think that the process has been good; I think it has been rushed. This has been a somewhat opportunistic way to introduce the legislation, although obviously I can see the necessity and urgency for it in relation to COVID-19. We certainly recognise that, as do all our members of Parliament. We are trying to get a handle on this legislation in trying times. We have had no time and no ability to consult with anyone who opposes the legislation. Our members of Parliament have limited ability to provide input into so many changes to the legislation. I represent the likes of the members for Warren–Blackwood, North West Central and Geraldton, who are out in their regions. We are here to represent them and they have had very limited opportunity to consider the bill.

I recognise the vulnerability of patients who do not have guardianship arrangements. The member for Hillarys went through that side of the legislation in detail. When guardianship arrangements are in place, people can make emergency decisions. The people who are looking after the patient or the next of kin looking out for the person's interests have opportunities to make decisions. In many ways, this legislation is about people who do not have those opportunities. We are speaking up on their behalf. The challenge for the government in bringing in this legislation at this time is the distinction between the definitions of "treatment" and "research". I made a couple of phone calls this morning to get some comfort, I guess, in some ways. One of those calls was to Dr Andrew Miller, who, as members know, is a spokesperson for the Australian Medical Association. I wanted reassurance from him about the legislation and I felt more comfortable after speaking to him. He ran through some of the issues regarding off-label use and medical research. I will quote a paragraph from the second reading speech regarding Dr Miller. It states —

> …if Parliament does not pass amendments to the Guardianship and Administration Act 1990, our doctors and hospitals cannot offer all Western Australian COVID-19 patients a chance to benefit from the trial therapies that are being used around the world.

It is really important that all Western Australians have access to drugs and treatments to give patients the best chance of a recovery. I would well and truly be in that boat, and, as I said, if I was talking about my parents and the like, I would like them, my wife, my sons and the like, to have that opportunity. Let me make it clear that that would be my intent there, that we give our researchers and doctors those opportunities. Having said that, the other person I spoke with this morning was Wayne Martin, QC. We had a good conversation and I feel more reassured after speaking to him. He spoke to me about some of the legislation's background and that the government has been working through this in the background over the last two years. He made me feel more comfortable in that we are facing a crisis and the government's legislation will give us that opportunity to sort out some of these guardianship issues. I would like to quote one of the support letters that he wrote, provided to us by the State Solicitor's Office. It states —

> In some of those cases it may not be easy to locate a guardian or responsible family member who can give consent on behalf of the patient in a timely fashion. In such cases, under the law as it currently stands, those patients will be denied experimental treatments which might save their life, and other patients will be denied the benefits which flow from comprehensive research programmes.

That sums it up for sure. No doubt we would all like that opportunity.

The bill worries me in some ways in that it has strayed from guardianship issues to research grants. This morning, we had a comprehensive briefing with Dr Fatovich, which some members previously mentioned. I understand the difficulties with research grants and funding when there is a short timetable. As the doctor explained, many of those research grants are spread out over a series of years. We need to deal with the immediate issue and, as I said, probably the biggest issue for me is that we have not had a chance to have a briefing with anyone who opposes the bill. We have had a day and a half on the run, dealing with other bills such as the Criminal Code Amendment (COVID-19 Response) Bill 2020 and the like, and we have not had the opportunity to get both sides of the story. I wanted to point that out.

I will run through a couple of points that the minister might be able to clarify for me. Is there protection for a medical researcher who is a doctor as well as the independent medical practitioner? If an independent medical practitioner makes that final call—I guess they are the third person in the chain, if you like—they also then report back on the treatment and how it went. I am concerned about protections for that independent clinician. The bill is heavily weighted towards research, as I pointed out, and there are provisions for the protection of the patient; however, in some ways, the research objective seems to be more considered than the protection of the patient. That needs to be taken into account. The hierarchy of decision-makers in the guardianship arrangement has been explained. Given there is the spouse, the de facto, the person with a close relationship with a candidate and someone who provides care, support and emotional support but who is not remunerated for providing that care and support, how can the

administrative process assess some of those points, especially remuneration? I think that is a little cloudy. We understand the chain with the next of kin, close personal relationships and the like, but the mention of remuneration is a little concerning.

I have a couple of other questions about data and tissue collection during a pandemic or an emergency situation. Are there guidelines around the collection of this data that protects the patient and clinicians working on the patient? Will it be intrusive and compromise the care of the patient? Will data and tissue collections be part of the pandemic research, or will it be used for continual research purposes after the pandemic? Once consent has been given for the administration of the trial drugs, what are the constraints on that consent? Can the guardian or patient be given the option of medical data being used, specifically for COVID-19, or will the tissue and data be presumed to be the property of the research facility? Those are some interesting questions that need to be addressed and I suspect we would have addressed those if we had a quite a bit more time. I would also like to point out comparison with jurisdictions. Apparently, five other jurisdictions have consent available, but Victoria seems to have a discrete bill, so I do not know whether the minister can give us any further information on that. I would be interested in whether we are lining up with other jurisdictions around Australia. Generally, under most legislation, that seems to be one of the main aims, so it would be very important to know that, but at this stage we have not really been able to get as much as information as we would have liked. With COVID information coming out on an hourly basis, I guess, how can a human research ethics committee be assured that the result of administering a trial drug would not be detrimental to the patient?

[Member's time extended.]

Mr P.J. RUNDLE: I assume that a human research ethics committee could not, in some instances, be fully confident that the drug would not be detrimental to the patient; therefore, how will the committee confer and respond to new drugs that are being trialled overseas? As I said, it is changing every hour, as the minister well knows, and that would certainly be one of the issues. We have seen some individuals advertise in the papers how they are contributing to research on different drugs and how they might be administered. We would like to know how they potentially could play out and how the human research ethics committee would be involved in the likes of those.

In conclusion, I want to point out and reiterate that at this time of crisis the Nationals WA certainly support this concept. We support the fact that people will have an opportunity to have potentially new research drugs coming to the fore and certainly, as I said, if I were on my deathbed, I would be more than happy to give those a try. We very much understand that. I believe that an amendment for a sunset clause would serve everyone well, because it would allow this research and treatment to continue during the COVID-19 scenario, but would give Parliament time—in a year's time, if you like, to give it a full year—to scrutinise this bill before a two-year sunset clause ran out. As I said earlier, some of the bill's ethical and moral elements are not too dissimilar to those contained in the voluntary assisted dying legislation. Some of these elements are quite controversial and we have not had an opportunity to talk to people who oppose the bill. I very much support the bill in a moral sense, and the feeling in our party room is that we well and truly support the concept.

We have received many inquiries about the regional travel restrictions that are in place. I know that the likes of the member for Central Wheatbelt, the member for Moore and my other parliamentary colleagues have said that people in the regions are taking social isolation and social distancing very seriously. Everyone is well and truly on board. We are supportive of the regional travel restrictions as long as they are administered in a commonsense way.

As was stated by the Minister for Health today, the number of confirmed COVID-19 cases in the regions is slowly building and the number of confirmed COVID-19 cases in the metropolitan area is building, with nearly 400 confirmed cases in WA. From what I can gather, the testing regime will increase rapidly. I am very hopeful, as per question time today, that our GPs in the region will be given support. I have had quite a bit of feedback from GPs who are really worried about personal protective equipment because some have basically run out of supplies and they are operating by talking on the phone to people in the car park, which is not suitable. I know that we have to support our public and private hospitals, but we also have to support our GPs on the front line. I have taken this opportunity to point that out.

Certainly, the Nationals are supportive of the legislation, but we would be very supportive of a sunset clause, similar to the sunset clauses in other legislation that we have dealt with this week. That would give us the opportunity for good scrutiny of the legislation. We would all feel very comfortable with that. I flag that I will be moving an amendment for a sunset clause during consideration in detail.

MS M.J. DAVIES (Central Wheatbelt — Leader of the Nationals WA) [3.32 pm]: I rise briefly to add to the contribution made by the member for Roe on the Guardianship and Administration Amendment (Medical Research) Bill 2020. I thank him for the role that he has played in picking his way through the numerous briefings that have been provided by the government in a very short time frame. He has been attending to and dealing with all those matters. We are all dealing with different circumstances. We have slightly fewer National Party members today

and everybody has stepped up to make sure that we can do our job appropriately. I echo the comments made by the member for Roe in that we will not, and do not want to, stand in the way of any legislation that might assist in the treatment of patients with COVID-19. From our perspective, it is the case of the government putting forward an imperfect solution, and we understand why, but saying that, the end justifies the means. That needs to be noted because when things roll out after the bill leaves this place, people will look for clarity to make sure that we did not simply rubberstamp the provisions in the bill without expressing that we understand that this is an imperfect situation and that the government and all of us are operating in very unusual circumstances.

Like other MPs, I have had very little opportunity to scrutinise the detail of the bill. We have had very little time to be briefed to test the concepts with key stakeholders and to canvass our party members to come to a conclusion. If members look around this chamber, obviously for the purposes of *Hansard*, there are very few people in here. As a consequence of Parliament having to adapt to maintaining a safe workplace, we have been asked to bring in only a certain number of members into the chamber and Parliament. Members of Parliament are in their electorates and are unable to contribute to the debate as they would normally do. That is challenging, and certainly we want to make sure that their views are heard while we have the opportunity. The reality is that some members cannot be here to ask questions, raise concerns, deliberate and contribute in person. We are all prepared, as everybody has said, to exercise flexibility in these uncertain times. They are pretty flexible times. The minister was on his feet before I could get to him to talk about the amendment that we are proposing. We had been meeting to get to a point at which the party would be comfortable to provide support without any concerns. We continue to ask for that understanding because we are doing everything to the best of our ability in good faith.

Mr R.H. Cook: I appreciate that.

Ms M.J. DAVIES: Thank you.

Despite the extraordinary requests from the government during debate on the Supply Bill 2020 and the Treasury advance bill to approve significant funds with very little detail about issues, the current budget situation or an indication of where the funds might be spent, we were willing to oblige these requests. We understand how challenging these circumstances are. However, this bill is a slightly different kettle of fish because it has application beyond the treatment of COVID-19. Although the government's intention may well be that this should focus the attention of our research community and health professionals to respond to and treat patients in a very fast moving environment, I have absolutely no doubt that a plethora of other trials will come into being as a result of this bill.

Going by the contributions of previous speakers and the few conversations we have had before coming here to debate the bill, there is certainly an appetite for that in the research community. I have great concern, as do my colleagues, that we are being asked to approve legislation that has been redrafted multiple times in the past two weeks without the proper scrutiny of Parliament. Regardless of the review that is being proposed, it will be part of our statutes in perpetuity, which is why the sunset clause that the member for Roe has proposed is appropriate. I have no doubt that research into all other significant illnesses and diseases is critical. Today we have heard some very heartfelt proposals and examples from other members who support the legislation. We would no doubt have the support of our colleagues in ordinary circumstances—we absolutely do—but we are here in this Parliament in these extraordinary circumstances to deal with legislation to respond to COVID-19. It is too difficult for us to amend the legislation to restrict the bill to COVID-19 because we do not have access to drafters. We have received wonderful support from the chamber staff, and we thank them for that.

Mr R.H. Cook interjected.

Ms M.J. DAVIES: They did, absolutely, but doing anything more complex, such as drafting to create amendments to restrict the legislation to only COVID-19 for a particular time, was beyond us in the time frame that we had. Drafters are not available to the opposition. I thank the Clerk and the chamber staff for their assistance. We are very grateful for that.

If we are being asked to step up on COVID-19, we are here and ready to do that. We are doing it with reduced resources, reduced information and reduced time, but we are doing our best. But the government is asking us to provide consent for a significant shift in medical research protocols that will be used beyond COVID-19. It may well be that after appropriate scrutiny, we would support the broader application of this legislation. We have flagged our intent of a two-year sunset clause in the legislation. That will allow the medical fraternity and those who fund it to kick their processes into play immediately without any restrictions. It will not limit or prevent the efforts of our health system to progress with the treatments that may well save lives and to pick up on that research in an international context. Because we are somewhat behind the curve in an international sense, we have the ability to apply some of those findings here in Western Australia and Australia. I note that there is concern that putting a sunset clause in place would potentially limit funding opportunities or disrupt any potentially lifesaving trials that are in place. I absolutely do not agree with that. The minister would need to have a compelling reason to be able to change my views on this. In two years, another Parliament will be in place. Work could be done on a new bill that could

be introduced to seamlessly fit in with the cessation of the legislation that we are debating today, so that any trials would not be disrupted. We will have two years to do that. That would allow the Parliament—all its elected representatives and committees—with its checks and balances, to do its job. This is a bill to achieve an end, but the means are broad and they will be used more broadly than just for COVID-19. All the briefings that we have attended from the medical fraternity and the briefings that we have had on the bill indicate that that will be the case.

Although there may have been an ongoing conversation for a significant time—I understand from as early as 2015, which was the time of the previous government—we certainly have not been across that conversation or had visibility of it, outside of a very small number of people. We accept that these are extraordinary times and we accept that this is extraordinary legislation. We would like to see some protections in place so that the legislation we are passing, with limited scrutiny, does not create ongoing unintended consequences. We have given the government an undertaking that we will not block the passage of the bill; we are not in the business of doing that in a state of emergency. I think our actions to date have demonstrated that. However, we do not really accept the arguments that have been put so far about jeopardising health research or not allowing those that need to do their job right now to get on and start doing it. I am happy to be dissuaded, but I do not think it would stop urgent treatment of COVID-19 patients, because the bill would operate as printed for a full two years. The debate occurring in this place now would indicate to research bodies, funders and future governments that we intend to come back and deal with this in a more appropriate manner in the fullness of time. We are here to assist the passage of legislation relating to COVID-19 and we are doing our very best. This bill goes far broader than just dealing with COVID-19. The minister's consideration of our amendment would be very much appreciated.

MR R.H. COOK (Kwinana — Minister for Health) [3.42 pm] — in reply: I thank members for their contributions to the debate on the Guardianship and Administration Amendment (Medical Research) Bill 2020. They have been thoughtful and I appreciate the tone and the spirit in which they have been made in this place. I rise to respond to the second reading debate. With the Deputy Speaker's indulgence, I will take this opportunity to make some broader remarks consistent with the scope that some members started with.

First of all, on a personal note, I thank members for their support for the government and, in particular, the work that I am doing on the COVID-19 epidemic. We cannot do this alone and I appreciate all the suggestions and cooperation from people. In particular, I will put on the record my appreciation of the work of the member for Dawesville and his assistance, and the opportunity essentially to work with him on a lot of these issues as they come up from time to time. This is a very difficult process and a difficult experience for the state. Knowing that I can, from time to time, take the member for Dawesville and other members in this place into my confidence in order to provide a way forward is greatly appreciated. I would also like to thank the member for Moore for the suggestion from his constituent about these matters. We will give that full consideration.

This legislation is not perfect, and we get that. This is not the way that one would ordinarily go about legislation of this type, but I want members to appreciate that this is not something that has been cooked up in the last few days as part, as the member for Roe suggested, of an opportunity. As all members have observed, this is part of a statutory review that took place in 2015, when I did not appreciate that it had taken place. Indeed, a lot of work was done on that. In particular, this was about an opinion from the State Solicitor in 2018 that the then current practices by medical research staff in our emergency department environments were beyond the legislation that they thought captured them. I want members to understand, from an historical perspective, that this is not activity that is about to take place. This is activity, and the nature of activity, that took place for the complete time that members opposite were in office. This is not an opportunity for these medical researchers to do new work. This is work that was being done for many years by the medical research community, but was stopped in early 2018 when some legal issues were thrown up. It has been the work of the Attorney General, and he has done an awful lot of it, to try to craft legislation that would capture that work. As a result of that, much liaison and stakeholder consultation has taken place to try to craft legislation in a way that keeps everyone happy—that is, both from a legal perspective and a research perspective. For many people in the medical research community, this is not the beginning of the journey, but halfway through the journey. They have been working on this legislation for a very long time because they want to get back onto the job of doing good medical research in an emergency department environment. They are desperately keen to make sure they can do it. As Minister for Health, I am desperately keen for them to get back onto the job as well, because we know that if our medical workforce is undertaking good research, it will improve care for our patients and it will mean that they are practising at the forefront of their craft. It will also mean that we attract the best and brightest of medical researchers and clinicians, which is good for the Western Australian health system.

Let us roll forward to the onset of the COVID-19 pandemic. We were in a position to see that we would be confronted with a lot of patients at end-of-life and critical moments. We need to have this legislation in place to ensure that we can provide those patients with the best possible care available, which means that we want them to participate in worldwide medical research and treatment projects to ensure that we have the very best level of care brought to their bedside. This

is not about a new opportunity for the medical research community; this is fixing a wrong in history whereby our medical research fell outside the statutes. We have been trying since early 2018 to redraft the statutes to capture this activity.

I think the member for Roe suggested that this was an opportunistic strategy by emergency department medical researchers to try to extend their reach and their activities beyond what they had ever been before. That is not the case. They have been doing this work for decades as part of the international medical research community to advance medical science and care for patients. We are not there yet. The legislation is not perfect. Many in the medical research community are disappointed in this legislation and are saying that it does not deliver everything they need in order to do everything they want in a medical research environment. They are saying this is good enough for now because we have an emergency, and that emergency is the COVID-19 pandemic. We want to basically put ourselves in a position in which Western Australian doctors, nurses and emergency department consultants can be part of this worldwide effort to find a cure or a better treatment to ensure those patients are cared for in a better way. Did the member for Roe want to interject?

Mr P.J. Rundle: It was more about the government being opportunistic in bringing it on, with a lack of ability to brief, I guess.

Mr R.H. COOK: This is not our preferred mode. A lot of work has obviously been done in consultation with those that we would normally expect outside this place, but this is not the way we would ordinarily go about things. We apologise. We know it is not perfect, but it is the best we have got for the moment.

I want to briefly address the concerns raised by the member for Hillarys about drafts and redrafts of the bill. I appreciate the flexibility of members as this bill was continually improved. We are working in a particularly fast-paced environment at the moment. Drafters, legal counsel and policy experts have worked day and night to try to get this in a form that is suitable for us for the moment. Members have referred to a number of different drafts, particularly the member for Hillarys. To explain: the government provided members with a draft bill prior to its introduction. At that point, our advisers had shared draft 14 with members. Following a briefing with members of the opposition and members of the National Party, the advisers worked with the Parliamentary Counsel's Office to make a number of amendments to the bill to reflect concerns raised by members. Those amendments were reflected in draft 21. That draft was provided to members, together with a document that had "track changes" turned on, to share what those amendments were. Member for Hillarys, draft 21 is the bill that has been introduced in Parliament and is what we are debating now.

I would like to step through some of the concerns that have been expressed by opposition parties. I want to place on the record the fact that we have consulted on this and that it is widely supported from within the medical research, legal and advocacy communities. From that perspective, what I will do is slightly unusual. I will table those letters of support so that members can see the arguments that people acknowledge so they can see how they have come to support the legislation. In support of the legislation, I table a letter signed by Pip Brennan, the executive director of the Health Consumers' Council of WA, and a letter signed by Associate Professor Glenn Arendts, the head of emergency medicine at Fiona Stanley Hospital, who refers to the submission made by the Royal Perth Hospital Human Research Ethics Committee. I also table the letter of support from the Public Advocate, which the Leader of the Opposition referred to in her address, as well as letters of support from Dr Andrew Miller, President of the Western Australian branch of the Australian Medical Association, and Hon Wayne Martin, AC, QC, who many people would know is the Chair of the Harry Perkins Institute of Medical Research. I table letters from Professor Daniel Fatovich, who many members have heard from, on behalf of the Centre for Clinical Research in Emergency Medicine at the Harry Perkins Institute of Medical Research, and Ms Anne McKenzie, a former chair and life member of the Health Consumers' Council of Western Australia.

[See paper 3315.]

Mr R.H. COOK: I want to speak about the issues that were raised by a number of members of Parliament. Before I do, Deputy Speaker, my apologies; I have one other letter to table. It is signed by Dr Simon Dimmitt, Hon Eric Heenan, QC, and Gorette De Jesus Garces on behalf of St John of God Health Care.

[See paper 3316.]

Mr R.H. COOK: A number of members raised the fact that the provisions are not time-limited in any way and are not limited to a pandemic emergency. The time-limiting of these provisions would impact research in progress as funding and ethics research governance approvals would only be able to be provided to the end date for which the legislation is effective. This may mean that the project will not be considered feasible. It is not clear whether the COVID-19 crisis will continue or whether treatments or vaccines will be developed within 12 months. Consequently, COVID-19 research may be directly impacted. The effect of limiting proposed section 110ZS, which a number of members have referred to, would mean that a patient who presented in an urgent treatment setting would potentially not be able to access new non-standard treatments, for example treatment that is still subject to a clinical trial, unless a decision-maker could be contacted in time to make a decision. I have been advised by all of the key

stakeholders to this bill that any amendments to limit proposed section 110ZS or introduce a sunset clause would undermine the bill so considerably that it would lose their support.

I note the observations made by the member for Hillarys that those people who would be subject to proposed section 110ZS would be very small. He said that only one or two people may miss out. In response, I say that this might save a life. The lives of one or two people may be captured by proposed section 110ZS. That is why we want to make sure that everyone has the capacity to benefit from this legislation.

A number of members asked why this bill allows urgent medical research without consent when recommendation 6.2 of the statutory review recommended against authorising medical research to be carried out on persons who lack capacity to consent to urgent situations. This was a point raised by the member for Hillarys. Recommendation 6.2 of the 2015 statutory review recommended that health professionals not be permitted to make any urgent medical decision on behalf of an incapacitated person. However, no person mentioned in the consultation summarised leading to recommendation 6.2 made that recommendation specifically. All of the people consulted accepted that urgent medical decisions could be made by doctors on behalf of incapacitated people. In particular, the Public Advocate has since voiced her support for this legislation. Hence, further consultation in 2017 led to the reversal of recommendation 6.2.

I was asked why it is important to conduct medical research in urgent situations. Urgent medical research relates to research occurring in emergency settings such as ambulance call-outs, emergency departments and intensive care units where there is no opportunity to substitute decision-making consent being obtained. The decision to enrol the participant in the research must be made within the emergency setting. This is a significant niche of research that focuses on the discovery and application of time-critical diagnostic-making and treatment that can save lives, prevent or reduce disability, and restore health.

There are a range of examples but we might take a situation about which there is a lot of discussion at the moment relating to the best treatment for COVID-19 patients, particularly those suffering a respiratory breakdown and the best ways to ventilate them. The emerging consensus is that a range of highly interventionist ventilations are more effective than non-interventions such as face masks and the impact they have. This has to be researched and experiments need to be done. We have to find out these things. Unfortunately, we do not have the time and space that many people would otherwise wish for in order to carry out the appropriate consents. Sometimes this can be a split-second decision about saving a person's life. It is crucial to understand that. For example, in a major trauma situation, a patient with acute and severe injuries is often unable to give valid, informed consent due to impairment from psychological distress, acute pain, lack of oxygen or blood supply or a reduced level of consciousness. However, the same distress may render next of kin family members incapable of providing consent. They may even have to have been involved in the same accident. Medical and surgical care, and trauma care is often performed without consent in emergency settings to avoid any delay that might risk life or patient harm. There is a range of settings in which it is absolutely crucial that the ED consultants are able to make a decision about the best interests of the patient.

There has been a lot of discussion about placebos. Obviously, it is necessary to have a placebo in place in a range of settings because we need to make sure that we have a control group and that we understand the impact and effectiveness of drugs on the care of the patient. Placebo refers to that instance in which a clinician does not know the nature of whether they are applying the drug, which is for the benefit of the patient. Without knowing the nature of the drug, that cannot influence their decision about whether to provide the drug. That is not to say that the clinicians are stepping back to simply watch the patient wither away and die. It is part of an overall program about caring for that patient while at the same time ensuring that none of the research that may or may not be taking place around that patient detracts from the care that they receive. A number of members have characterised this as in some way not providing the best possible care. It is nothing of the sort. It is simply a matter of making sure that when there is an opportunity to care for a patient, variations on the themes around that patient's care, drugs and treatments that produce a better outcome are available to them. It is not a case of neglecting that patient or ensuring that they do not receive the usual clinically-derived treatment that is appropriate. For that reason, if we are to provide clinical excellence in some instances, we cannot always be in a position to reach out to that person's decision-makers. However, at all times, we must make sure that the treatment the patient receives is within the clinical framework and there is nothing that we are doing that, in the view of the patient's doctors, detracts from that person's care.

The member for Hillarys made the comment that we should not let the perfect get in the way of the good. I could not agree more. That is what this legislation is about. It is about making sure that we have something in the legislation so that we can be part of the international research community. We cannot do that if our clinical leaders have one hand tied behind their back. They have been doing this work for many decades as part of the Australian research effort and the international research effort. It has stopped in the last couple of years simply because of a legal glitch that we needed to amend. We are reknitting our research community back into this international network of researchers across the globe to ensure that we can play our part in practising at the forefront of medical excellence and clinical excellence in supporting the COVID-19 outbreak and fight. I think the Leader of the Opposition gets this. She made

an excellent contribution to the debate in her speech this afternoon. She provided unequivocal support for our medical research community. The legislation in the other place around the future health research and innovation fund is another vote of support for our medical research community. I thank the opposition for its support for that legislation also. This is about how we save lives when all else has failed. How do we ensure that those people in critical care have that extra opportunity to get better treatment and better medication and get the support they need? The Leader of the Opposition's unequivocal support for this legislation is welcomed. I noted her comments about the sunset clause and the discussions I had with the member for Hillarys around those issues. I thank her for her support and our gentle resistance of those particular amendments.

In my second reading speech, I confirmed that we would certainly support a reference to the Education and Health Standing Committee so that the legislation can be further reviewed by the Legislative Assembly and other members of Parliament. I know that this committee has a particular membership at this point, so I support other members being co-opted onto that committee, obviously with the support of the committee members themselves. I am looking at the member for Dawesville, the deputy chair of that committee. This is of acute interest to everyone. I note in particular the Nationals WA members' concerns about this bill. It is really important that they have an opportunity to get amongst the committee and have a look at it. Members of the National Party who join in that inquiry will see that this not a new thing; this is something that medical researchers have done for many years. In Western Australia, we have simply been trying to get the legal framework right. We have not quite cracked it yet, in the view of a lot of people in the medical community, but we have come a long way and, from that perspective, this legislation is extremely important.

I wish to table the letters that I sent to Hon Alison Xamon; the Leader of the Opposition, Hon Liza Harvey; and the Leader of the Nationals WA, Hon Mia Davies, for the information of members.

[See paper 3317.]

Mr R.H. COOK: I would like to thank the Leader of the Opposition for her comments confirming that the Liberal Party will not be supporting the sunset clauses. That is an important issue. I want to dig into why the sunset clauses would be problematic and speak to some of the practicalities in detail. The grants to fund the research often span between three and five years. As I noted, although ethics committees have approved elements of clinical trials, they have not been able to approve parts without the legislation before us. With a sunset clause, they may still be unable to grant approvals because they will be on notice that the legislation would expire in two years while the trial may span anywhere from three to five years. Research staff are employed for the duration of the grant. What would they do if the research suddenly stopped before completion? Research infrastructure and skills take time to develop. We also need to value research as an integral part of everyday clinical practice. It would be unethical to cease research before completion. For multicentre trials, if WA fell over, it would impact on the other sites, as many of these research trials are part of the national and international global network of medical research. For Western Australia to play its part, we have to be able to run the full course of the trial. The research would take longer and we would risk wasting the public's money if we were unable to participate fully. There is also substantial competition to attract research projects to WA. Unless there is guaranteed continuity of clinical research in WA, no projects, centres of excellence or funding will be awarded here. We need to retain the best researchers in WA and we can do that only if we have a legislative program that enables them to do their work. As the Leader of the Opposition noted, any sunset clause that undermined ongoing research would be highly problematic.

The member for Nedlands raised concerns that the medical research would not be limited to simply COVID-19 research projects. There is a reason for that. This is about setting up the framework. We cannot be half-baked on this; we have to be a fully-fledged member of the research community. We have to establish the full framework for this and not simply try to pick and choose aspects of it. That is why proposed section 110ZS is so important. We have to be a full research centre of excellence, not a half-baked one. It is an incredibly important aspect of this work.

As the member for Cottesloe said, relatives are not always available, unfortunately. Many of the next of kin, particularly in a trauma situation or, as we are discovering, in an infectious disease situation, might be impacted by the event or the disease.

The member for Roe asked a number of questions and I thank him for that. Obviously, like many members, he has not had an opportunity to get amongst this legislation yet. That being the case, the member dug in and had some good thought-provoking questions, so I want to go over some of those. I have addressed the fact that this is not voluntary assisted dying; this is not a new claim for opportunity. This is about reinstating a practice that had taken place in Western Australia for many years and was suddenly halted in early 2018. The member asked whether there will be protection for an independent medical practitioner. Yes, there will be, but only if they operate inside the guidelines handed down by the human research ethics committees. Obviously, these committees provide very strong frameworks for how the research will be undertaken, the circumstances under which it will be undertaken and the ethics that govern it. Obviously, the medical practitioners will have to make a decision inside that particular

framework; they cannot go outside it, but in that context they will be protected in playing their role. They will be protected as an employee in a public hospital.

The member raised issues about the remuneration. Simply, the professional carer of a patient from whom consent has been sought cannot be the person who provides consent. It will have to be someone who has a personal relationship, not a professional relationship, with the patient. He also asked a question about who owns the tissues and samples. Unfortunately, that goes beyond this legislation. I wish the Attorney General was under the age of 70 years, because he would have been able to answer these difficult questions for the member. I am doing my best, but I am sorry that I cannot assist him with that.

We have not had the chance to examine the Victorian legislation. The member asked about other jurisdictions. I can assure him that this is about Western Australia playing its part in the national landscape. This stuff is going on in every emergency department in the world. Every ED in the world is undertaking this form of research. WA is the only place where it is not taking place because of the legal glitch we have that we are, only in part, remedying today. That is why it is so important that we pass this legislation. If we are to participate in the work that Victoria, New South Wales and Queensland are doing to find new insights into how we can better treat people in a critical care situation, we must have this legislation in place.

I am paraphrasing the member, but he asked how the human research ethics committees can be sure that the treatment will not be harmful. By the time it is applied to humans, a lot of phases of the clinical trial will have been undertaken. These treatments, particularly drugs, are practised on humans only when they are very confident that it will have a positive impact. That is why I would not want to be a mouse today! A lot of work goes into making sure that they understand the general impact of these sorts of drugs and other treatments before they go to a fully-fledged trial, particularly in a global context. The member heard the Leader of the Opposition talk about one particular instance in which a new drug was discovered in one part of the world and was applied to someone in Western Australia within 72 hours. That is incredibly unusual. From that perspective, we are always confident. It is part of the job of the HRECs to make sure that they understand the nature of the treatment or drug that is being trialled to ensure that it will do no harm.

At the end of the member's speech, he mentioned issues around country clinics and general practitioners in regional areas. I want to reiterate the comments I made during question time today: we are working very closely with the rural health network, the rural health association and the WA Primary Health Alliance to support our GPs in rural communities by not only providing personal protective equipment, but also giving them good information so that they can understand the unfolding situation with COVID-19. A moment ago, I spoke with the chief executive officer of the WA Primary Health Alliance about the work that it is doing at the moment to roll out its COVID-19 clinics throughout regional Western Australia. She talked about how she is working really closely with the rural doctors network to make sure that we better support them.

I appreciate the issues raised by the member for Central Wheatbelt, the Leader of the Nationals WA, about a sunset clause. It will hamper, unfortunately. We need to make sure that Western Australian researchers participate in this on the same basis as medical researchers right around the world. We want them to be part of the international effort to find new treatments and new medications for COVID-19. That is why it is particularly important that we are not hamstrung by a sunset clause, because other jurisdictions would look at us and say, "You're not in it for the long haul. We don't want you to be part of this." A longer term research project would be hindered by a sunset clause.

The member for Central Wheatbelt made the observation that this is very broad and will apply to other research. That is true. This is about a framework that will greatly assist the COVID-19 response. It is not about saying that this can be done only for COVID-19 and nothing else. Other complementary treatments and programs that impact on COVID-19 patients might also impact on other patients suffering from respiratory illnesses or infectious diseases. It may not be a discrete cohort; others may also benefit from COVID-19-related research. We want to make sure that we are all part of this.

I place on the record my thanks to members for responding so quickly on this bill. It was not our intention to bring this legislation to this place at this time. It was our intention to continue to do the hard work being undertaken by the State Solicitor's Office, the medical research community and advocates to make sure that we got a much fuller piece of legislation. These are the changes that have been put in now so that we can get on with the job in front of us. No-one is 100 per cent happy and no-one has walked away from this getting everything they want. We have worked closely with all the stakeholders who are impacted by this—patients, advocates, civil rights organisations, researchers and our legal counsel—and put in place what we believe is appropriate legislation that will make sure that Western Australia can stand with all the other jurisdictions in fighting COVID-19. As the member for Dawesville said, this is a huge challenge for us all. We will never again confront a challenge of this size in our time in this Parliament. It is one that we must all work together on. I greatly appreciate the spirit with which members have approached this legislation and the speed with which they have considered the detail of this bill so that we can see

a speedy resolution to it. I place on record my thanks in particular to the Leader of the Opposition for her party's support for this legislation and I look forward to the continuing debate.

Question put and passed.

Bill read a second time.

Leave denied to proceed forthwith to third reading.

Consideration in Detail

Clause 1 put and passed.

Clause 2: Commencement —

Mr P.J. RUNDLE: I move —

Page 2, after line 7 — To insert —

(ba) section 14 comes into operation on the day after the period of 24 months beginning on the day after assent day.

As the minister is aware, we are supportive of the bill. I note the minister's comments during the second reading reply. We do not want to hold up the process by any means or stop research or the like. This is about scrutiny. As I said in the second reading debate, it is about having more time to look at the various clauses. I spoke about the difference between the fourteenth and the twenty-first draft, which we are now on. Apparently, in four days, the bill had gone from its third draft to the fourteenth draft. This is a changing world. Some of the amendments have originated from my research officer. It concerns me in some ways that we have provided a couple of those amendments. As I said earlier, due to the change in standing orders, regional Nationals WA members who are not here have not had time to scrutinise the legislation and we have not had time to talk to anyone who opposes the bill. We certainly are not contesting the intention of the legislation. We very much support it. As I said, if I were in that situation, I would like to have treatment available that might save my life. This is about giving members here and in the other place the opportunity to scrutinise the legislation.

Mr R.H. COOK: I thank the member for his contribution and acknowledge the work that he and his staff have done to understand the legislation. I appreciate the questions the member asked. They certainly demonstrated good insight, and I thank the member. This amendment would introduce a sunset clause. I spoke about that at length just now. We do not support a sunset clause. We believe it is unnecessary because we have agreed to refer the bill to a parliamentary committee. This will take place in the blink of an eye. By the time we get ourselves through this difficult patch of COVID-19, we will be into the task of reviewing the legislation and making sure that, as legislators, we have good insight into the bill. I appreciate what the member said. He called it a drop-dead clause. We do not want to hinder or tie one hand behind the backs of our medical researchers and people on the front line. From that perspective, we gracefully decline the member's offer to amend the legislation. The ability of our researchers to be part of long-term projects is an important part of our medical research ecosystem. From that perspective, the government will oppose the amendment.

Mr R.S. LOVE: I understand that this legislation has been around and thought about as far back as 2013 and that a review was done in 2015. I understand that this legislation has had 21 drafts and that it was being reviewed as late as last night. The idea that this legislation should stand in perpetuity, given the rush we are dealing with it, is unseemly. It is not normal parliamentary process. If these were normal times, an upper house committee would go through this very closely and undertake a proper review. We are being asked to send this to the upper house and for it to make a decision on it in a matter of hours. That is not the normal process yet we are being asked to put this legislation on the statute book forever. I understand the intention to send the bill to the Education and Health Standing Committee. I am a member of that committee. Without casting any aspersions on the role of that committee, in my opinion, it is not a body that can effectively review a very important piece of legislation such as this. It does not have a track record of doing that. Furthermore, after undertaking that review, there is no guarantee that the government would look at what was proposed and take on board any of the committee's recommendations.

We have put forward a two-year sunset clause. Some other bills we have passed in this sitting have had a sunset clause of one year, which would mean that the legislation would be guillotined just after the next state election. That would be untenable in this situation because people may be receiving treatment. This legislation has been brought on under the guise of COVID-19 treatment and research, but the justifications around it are not to do with COVID-19 treatment and research. If we talked about just the COVID-19-related situation, which is what we are supposed to be shortcutting legislation to enable, by allowing a sunset clause of two years, the new Parliament after the next election would have a full year to decide whether it wanted to allow this legislation to fall over or, indeed, simply bring it back and remove this addition to clause 2, which would leave the legislation intact. It would be very simple for the next Parliament to handle this, but there would be this provision that, unless Parliament makes a conscious decision to the contrary, this legislation would fall away. We would also suggest that those

two years be used to send this legislation to the Law Reform Commission to enable it to have a very good look at it and come back with some considered and highly detailed understanding of this legislation, and allow this to be decided by the next Parliament, not immediately after an election, but midstream; and if not decided within two years, then three years, but two years would allow that process to occur and the COVID-19-related aspects of this legislation to be addressed to get us through this period. If the government wants to introduce a whole raft of other legislation using the guise of COVID-19 to shorten the parliamentary processes, I think that is short-changing the parliamentary process of this state, and I do not think it should be allowed without challenge. That is why the Nationals WA are standing up on this as a matter of principle. We support the legislation; of course we do. We want people to have access to it. The member for Roe might want to keep me going!

Mr P.J. RUNDLE: I would like to hear some more from the member for Moore.

Mr R.S. LOVE: I was just preparing myself for the next few moments.

We support this legislation—have no doubt. I think the minister inferred that we were not supporting the legislation. That is not true; we support the legislation. What we do not support is allowing this legislation to extend to a raft of other things unrelated to the COVID-19 situation, because we are using the COVID-19 temporary orders to shorten the parliamentary process. If this bill is to apply to a whole range of other things, quite naturally, as parliamentarians, we believe that the legislation should come back to Parliament—not to a committee of the Parliament that can be ignored by the government of the day—for review in this chamber and the other place. That is the proper process that should be followed in this situation. To say that this would affect a raft of other types of research other than COVID-related research takes it right out of the sphere of the COVID-19 temporary orders. The COVID-19 temporary orders of Parliament deal specifically with matters related to the COVID-19 crisis that we face in this state. The government is asking to bring in legislation carte blanche that touches on that, but also expands to a wider raft of legislation. That is why we are standing up on this. We believe that yes, we should have leeway to help in the current situation to enable Western Australian hospitals, doctors and researchers to participate in a worldwide effort to try to bring about solutions to this debilitating situation that every country in the world is facing. We are not opposed to that at all. But the government is suggesting to extend this to a whole range of other research situations, which should ordinarily be put through the normal processes of Parliament.

For that reason, I am supporting the position put forward by the member for Roe and the position strongly supported by the rest of our team, who are absent from Parliament at this time but also share our concerns about the lack of due parliamentary process, which has been given to a bill that is not without concern from others in the community. They have not had an opportunity through this process to come forward with their concerns. Just before I stood up I got an email from a group, that I think has emailed every member of this chamber, expressing its concern about this bill.

Mr P.A. Katsambanis: They have not emailed me.

Mr R.S. LOVE: I am pretty sure that the member for Hillarys must be the only member of Parliament who is not on the list. Perhaps it has gone to the member's office; I do not know. But there is a very long trail of names on that email that I just received.

I think the Western Australian community expects Parliament to react to the COVID-19 disaster. We are, as a party, quite prepared to give the Western Australian government every tool it needs to deal with this situation. What we will not allow is a raft of other measures to be introduced under the COVID-19 guise that extend way beyond the situation that we face with COVID-19, and that reach into other areas that have been kicked around for years. The whole idea of the amendments to the legislation that have been put forward with this bill have been discussed. Quite frankly, they should be put through a process, not a review from a committee, but a full parliamentary process in which the bill is required to be re-debated and put through the normal reviews of the Legislative Council, for which there is not time in the current situation.

Mr P.A. KATSAMBANIS: I think this amendment is motivated from the best of intentions. We are at an impasse here. We have legislation that quite clearly has a series of question marks around it. We are being told we must rush it through because it is urgent given the severity of the COVID-19 crisis that we are facing. But it is legislation we have also been told will partially apply to COVID-19, but really, its major application will be on an ongoing basis in other forms of medical research. That is fine and good; we recognise that. The member for Roe has proposed this amendment, which gives effect to a sunset clause that he will move subsequently if we pass this amendment. A sunset clause may be one way of dealing with the issue that we have. It may very well be that two years, as proposed here, would be sufficient to firstly get over the COVID-19 issue, and, secondly, look at how it applies on a more ongoing basis. However, the risk we run with any sunset clause is: what would be the consequences upon that sunset? The member for Roe can correct me if I am wrong, but I believe he is sunsetting the entire bill after two years; I have not seen his subsequent amendment yet. He nods in affirmation. Hansard cannot record that, obviously, but the member for Roe nodded in affirmation that that is the case. By sunsetting the entire bill, the

research that can be conducted under proposed new section 110ZR would also cease. In the main, we seem to all be in heated agreement that that part of this legislation, other than some of its perhaps technical elements, would not be controversial in any way. It is not that we have identified any issues in its technical elements, it is that we have not had any time, other than the time we have had between Monday and now, to look at how it will operate, to interrogate it and find out from other people what they think this will mean in practice. I am not saying there are technical flaws in it. In fact, I said in my contribution that what has happened in those three days has seriously improved the legislation, significantly so, and added some serious safeguards.

I am torn. The Liberal Party is between and betwixt as to whether sunsetting is the right way to go. I seek from the minister a lot more clarity about the intentions of a review. Will it be a 24-month review or a 12-month review? From the time I sat down until now, has there been any further movement in what is likely to take place, because the review clause in the bill is 24 months but in a letter that the Leader of the Opposition read out, the offer is a review clause of 12 months? Will an amendment be made and will an amendment be made here or in the other place?

Mr R.H. COOK: I thank members for their comments. Just going quickly to the point made by the member for Hillarys, my second reading speech stated 24 months all the way through. The bill we are debating states 12 months because there was a late change. On behalf of the government, I apologise to the Parliament for that inaccuracy in my second reading speech. Proposed section 110ZZE provides that the minister must review the operational effectiveness of this part and prepare a report based on the review as soon as practical after the first anniversary of the day on which the act comes into operation. My apologies for that misunderstanding.

In response to the member's comments, obviously, as I said, we will not support the proposed amendment. The Leader of the Nationals WA made the observation that this would put it in place in perpetuity. Nothing is in perpetuity in law. We are the masters of our own destinies and from that perspective nothing that we do is in perpetuity because another Parliament may seek to amend it. In addition, we will review the legislation after the first 12 months and it will be the role of that committee, I suspect, to get on with the job and make sure that it takes the opportunity to really understand the legislation and its importance. Unless we can guarantee continuity of research beyond that period, research projects will not start here. We cannot expect our medical researchers to go into the field of battle with one hand tied behind their back. I understand the member's concern when she said that this is about all research, not just COVID-19. This is not necessarily about COVID-19; this is about the vehicle by which they will address issues of COVID-19. I appreciate the member's comment that this is somehow a wider ambit than simply COVID-19, but it is not; it is about the framework. We are building the car and obviously those in the driver's seat will decide which direction the car goes in. What we need at the moment is all guns blazing on the COVID-19 outbreak.

The inquiry can start at any time. I am sorry, I did not realise that the member is on the Education and Health Standing Committee. I apologise. If he is a member—the deputy chair is here—I suspect that the process can commence at any stage and it can be watched in situ over the next 12 months to get an informed view about how it works.

The member for Roe said that we have not heard from anyone who opposes this legislation. Potentially, that is true. We have discussed it with consumers, the Public Advocate, researchers and people of high legal eminence, and none oppose it. Some think that it can be improved in a way that does a little bit more of this and a little bit more of that, but all of them think that at the moment, this is where we need to be and this is the legislation we need in the current crisis. No stakeholder has come forward to oppose the bill in the period that it has been debated, and we have been working on this since coming to office. Discussions continue about how to improve its fundamental features have widespread support throughout the research community. As I said, people have been doing research in EDs for a long time; when the opposition was in government and when we were in government prior to that. This research goes on all the time in every ED in every part of Australia and every part of the world. We simply want to be part of the show.

Mr P.A. KATSAMBANIS: Again, this shows the moveable feast that we are dealing with. This is not a criticism of the minister or his staff, but the minister has just admitted that the second reading speech was erroneous in a material particular. I have not had the chance to look at what the explanatory memorandum states so I am not sure whether it refers to 12 months or two years. I will quickly flick through it. Perhaps the minister knows. The explanatory memorandum states one year. That shows the haste with which we have been working to get this bill to this place. Again, it highlights the need for a go-slow. A 12-month review is good. On balance, it is probably better than a two-year sunset clause, but again it raises the spectre of what the machinery of government does with reviews. I hark to the example of the genesis of the bill that we are dealing with. I believe that the review probably commenced in late 2013 or early 2014. It was tabled in the Parliament at the end of 2015 with 86 recommendations. Here we are, four years and four months later, considering the first two of the recommendations that have been progressed. With any statutory review we run the risk of the machinery of government taking its time. The cogs are not even connected, let alone working together, to get an outcome. That is not a criticism of this government, nor is it a criticism of the previous government; rather, it is a criticism of government across the board. It seems to be particularly rife here in Western Australia. We can get the review underway but after years and years, we get

no outcome, as we are seeing now with what we are dealing with. Yes, the parliamentary committee can undertake a review earlier, which is great, but the minister indicated in his second reading speech—I described it earlier as sotto voce; it was not quite sotto voce, nor was it a whisper, but it was off the script and not in the second reading speech—that he may provide terms of reference for that committee. However, a prorogation is coming up probably at the end of this year so any committee work that commences this year will necessarily end by the prorogation of Parliament before the election, and then, upon return, the committee will be reconstituted and it will have to kick off again. Again, the process of government could drag things out rather than speed things up. I am not convinced that a 12-month review is the way to go because of the reasons I have outlined. I am not necessarily convinced that the committee process will be any better simply because of the election intervening during that 12-month period. I am also really conscious of the unintended consequences of a sunset provision because procedures get put into place, research commences and then there are the unintended consequences of a sunset provision, particularly for ongoing research at the commencement of the sunset provision. We are talking about relatively intrusive medical treatment-based research that could be working on people. I remain firmly agnostic on it all. I am happy to hear out the continuation of the debate, but I am not necessarily sure that any of the solutions proposed are the best possible outcome that we can get to.

Mr R.H. COOK: I think we all accept that we are part of an expedited process here. I apologise for the inconsistency between my second reading speech and the changes that we have made to the bill. We made that change to the bill because the member's side requested it. That is what it wanted. It came to me yesterday and said it had concerns about the two-year clause and asked if we could reduce it to 12 months, and I said yes.

Mr P.A. Katsambanis: I am saying that 12 months is better than two years.

Mr R.H. COOK: That is right.

Mr P.A. Katsambanis: But is it the best outcome we can get? Not in my opinion. That is my opinion.

Mr R.H. COOK: In the opinion of the member's leader and shadow minister, it is a good outcome. I acknowledge the member's concern about the process, the speed, and the time he has had to deliberate over this. All those things have been acknowledged. The member should understand that what we are trying to achieve is not the perfect situation, but it is the best situation that we can achieve under the circumstances. That is why we are putting this legislation in place.

Mr Z.R.F. KIRKUP: I, too, rise to speak to the amendment moved by the member for Roe, my good friend in the Nationals WA, which, unfortunately, I will not be supporting at this time. I apologise.

I remain concerned about the idea of a sunset clause for a variety of reasons that we have expressed in this place already. Not the least of my concerns is that if a clinical trial were underway, this amendment might cause it to stop in some way, shape or form, which might have a negative health impact for a patient. Two years is a substantial period and I appreciate that the member for Roe has given it deep consideration. The concern I have is that if a clinical trial were already in place, I have been told that there is a risk that stopping it could have a negative impact. If there was already a program afoot, it would have to cease. As the minister has articulated, I personally believe that it is a good thing to have a provision for a 12-month review. As the Deputy Chair of the Education and Health Standing Committee, for as long as that committee is currently constituted, I think that that committee is well placed to look at this, as an option. I have to disagree with my good friend the member for Moore; I do not think the committee is incapable of dealing with this legislation in any way, shape or form. Co-opted members could be on the committee to take a look at this legislation and we could have a look at its implementation.

Aside from any changes that might happen in the other place, this initial provision, which has been reached by the Minister for Health together with the Leader of the Opposition, is a good one and one that we support. That is why, at this time, unfortunately, we will not be supporting the member for Roe's amendment.

Mr R.H. COOK: I thank the member for his support. This is an important policy position that we have to nail. Implicit in this amendment is the policy position that it is bad for doctors to make decisions in the interests of their patients within a constrained and substantial group of safeguards. We believe that it is appropriate for doctors to make these decisions. Implicit in this amendment is the idea that the Nationals think it is a bad thing and they want the whole thing to be over and done with. We believe that it is an important part of the legislation. I understand the spirit in which they have come to this. They are concerned that they have not had an opportunity to be provided with analysis of it, but the safeguards that have been built around this have been supported by health consumer groups, the Public Advocate and research ethics committees. No-one within the sector believes that the safeguards will not be substantial enough to make sure that we safeguard the interests of the patient.

This is an important piece of legislation because we want our researchers to be part of the international fight against COVID-19. We want them to be part of other fights as well, but that is not the point here. The reason we

have moved swiftly to get the car assembled and up and running is that we want to drive it in a particular direction. We need to make sure that we have this legislation in place. In an act of good faith, I brought forward the two-year review clause to 12 months. In an act of good faith, I agreed to supporting that a parliamentary committee undertake that review. I am being asked to take a further step, and I humbly submit that I am not prepared to take it. I think we have gone far enough to accommodate people's concerns about this. As I said, we will not be supporting the amendment.

Ms M.J. DAVIES: I rise to support the amendment moved by the member for Roe and to respond to some of the assertions that have been made. We absolutely support this bill. There is no question of that and I think it is evidenced by the fact that we have not sought to move any other amendments to the specifics of the legislation. I am not in a position to be able to question the framework—the safeguards the minister has referred to or the way in which the bill has been drafted to allow for clinicians to make these decisions—not the least reason for which being that we have not had time to do it. We are putting a great deal of faith in the minister that that is something that is needed to respond to COVID-19 right now.

Our point is that because of the broad application of these powers, a very clear message needs to be sent to the broader community that there will be a significant review of this legislation. We are trying to find a way for it to be brought back to this place so that every single member of the Parliament—it will be a new Parliament at that time—will have the opportunity to scrutinise the legislation and go through that process. This legislation may well have been around for a long time. It may well have been scrutinised, debated and haggled over behind the scenes for a long time. I simply ask for an explanation of why it has not come to this place. If it has been so well thought through and has been so well discussed, what has blocked the government from bringing it into this place so that it could be debated prior to this time? The suggestion is that at this point it is all okay and there is nothing to see. That may well be the case, but there was clearly an issue, because it had not arrived on our desks for debate before now. I said this in my second reading contribution, but I do not think it is beyond the wit of a future Parliament to take into consideration the fact that we are making decisions today in this very extraordinary circumstance in relation to COVID-19 and understand that we have put a sunset clause on the legislation.

A future Parliament—a future government—could put in place the requirements to have the legislation put back into the Parliament for everyone to debate and it could be seamlessly transitioned. Any clinical trials that are in place, which people have said may well be in jeopardy, could be managed. It is two years. We would be well into a new term of government, so there would be plenty of time to respond. Again, I return to the point that if this has been so well canvassed, why has it not been in this house before now? Clearly, there have been drafting issues between the medical and legal fraternities that have prevented it from arriving and being in place. We have all spoken about how important it is for research to be conducted for the benefit of all our fellow men and women in the state. I do not think anyone in this house would disagree with that, and I will not have any members of my party painted as such. I reject that. I am simply saying that this is something we are willing to consider. We have offered our support, but we want some safeguards in place because there has not been scrutiny by this Parliament and these elected members—the process of checks and balances of a normally elected government and Parliament. I do not think that is too much to ask. I accept that the government is not accepting it, but what I will not have is our party or our members being painted as individuals who do not support the intent of the legislation, which is to respond swiftly to COVID-19. We appreciate that the Minister for Health has undertaken, in the very quick conversations that we have had over the course of the last two days, to actually move to put in some of those safeguards. We certainly discussed those within our own party room but ultimately landed at this point. As we have explained previously, we had limited time to come back to the minister and continue those discussions. We ordinarily would have done that. I just put on the record that we understand that there is no support for this.

Mr R.S. LOVE: Acting Speaker, I would like to hear more from the member.

Ms M.J. DAVIES: It is disappointing from our perspective. I do not believe we have put this in terms that is beyond the wit of a future Parliament to try to manage some of the challenges that have been put forward. It is obvious that because negotiations about this legislation have happened for so long behind the scenes, there is no willingness to reopen that can of worms. I am comfortable with that, but I would like that to be acknowledged as part of the debate, not because what we are putting on the table is unreasonable or something that could not be considered in ordinary circumstances.

Division

Amendment put and a division taken, the Acting Speaker (Ms J.M. Freeman) casting her vote with the noes, with the following result —

Ayes (3)

Ms M.J. Davies	Mr R.S. Love	Mr P.J. Rundle *(Teller)*

Noes (23)

Ms L.L. Baker	Mr W.J. Johnston	Mr S.J. Price	Mr P.C. Tinley
Dr A.D. Buti	Mr D.J. Kelly	Ms R. Saffioti	Mr R.R. Whitby
Mr J.N. Carey	Mr Z.R.F. Kirkup	Ms J.J. Shaw	Ms S.E. Winton
Mr R.H. Cook	Mr F.M. Logan	Mrs J.M.C. Stojkovski	Mr B.S. Wyatt
Ms J.M. Freeman	Mr S.A. Millman	Mr C.J. Tallentire	Mr D.R. Michael *(Teller)*
Mrs A.K. Hayden	Mr Y. Mubarakai	Mr D.A. Templeman	

Pairs

Mr V.A. Catania	Mr M. McGowan
Mr I.C. Blayney	Mr M.P. Murray
Mr D.T. Redman	Mr J.R. Quigley

Amendment thus negatived.

Clause put and passed.

Clauses 3 to 13 put and passed.

Title put and passed.

Third Reading

MR R.H. COOK (Kwinana — Minister for Health) [5.09 pm]: I move —

That the bill be now read a third time.

I want to thank everyone for their participation in this debate on the Guardianship and Administration Amendment (Medical Research) Bill 2020. This is an unusual legislative process in unusual times. I appreciate that all members have brought the right heads to the process. I thank the Leader of the Opposition and the members for Dawesville, Hillarys, Roe and Central Wheatbelt for their assistance. I want to thank all those who worked on the bill. It was a piece of work that was almost complete but not quite complete. People from all sectors associated with this bill have come together to at least draft a bill that is workable and one that we can go forward with. I would also like to acknowledge the Attorney General, who is probably watching this online, being one of the fittest 70-year-olds I have ever met. Because he is over the age of 70, he has to stay indoors. I appreciate him giving me the opportunity to shepherd this piece of legislation through this place. I also want to acknowledge the President in the other place, Hon Kate Doust, who has been instrumental in the work that she is doing with the Precision Health Council to make sure that the opportunity for this legislation was seized. Once again, I thank all members for their participation. I commend the bill to the house.

Question put and passed.

Bill read a third time and transmitted to the Council.