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Hon Tjorn Sibma; Hon Nick Goiran; Hon Dr Sally Talbot

GUARDIANSHIP AND ADMINISTRATION AMENDMENT (MEDICAL RESEARCH) BILL 2023

Second Reading

Resumed from 22 February.

HON TJORN SIBMA (North Metropolitan) [2.00 pm]: I rise on behalf of the opposition as the lead speaker on the Guardianship and Administration Amendment (Medical Research) Bill 2023. I should identify very clearly at the outset that the opposition supports this bill. The bill is, in itself, actually straightforward, but it covers very important ethical and legal issues. I anticipate making remarks on those issues in my contribution, and they are likely also to motivate the contributions of the other speakers who I understand wish to put on the record their remarks in respect of this bill.

What does this bill do? It proposes two key things. The bill deals with an earlier iteration of legislation that came through this chamber under different circumstances some three years ago, and attempts to change the definition of "lead researcher" to encompass a broader range of health practitioners other than the more restrictive "medical practitioner". These health practitioners—either 15 or 16 or so occupations—are listed under the Health Practitioner Regulation National Law.

The second issue that has focused minds—probably a matter that has motivated more focus than is necessary, but I will get to that—is the removal of sunset clause provisions that were inserted into the legislation as a safety mechanism when the bill's passage through this chamber was expedited three years ago. If not amended under this legislation, those sunset clauses will prohibit incapacitate people from being enrolled in urgent medical research from April next year.

The issues we are dealing with have a history longer than just the last three years. In 2015, the then government tabled the *Statutory review of the Guardianship and Administration Act 1990*. There were some 86 recommendations in that report. Two of them are relevant to this bill and to the preceding legislation of three years ago—recommendations 5 and 6. Recommendation 5 states —

Recommendation 5: That Part 9A of the *Guardianship and Administration Act 1990* is amended to include a notice provision in relation to enduring powers of guardianship similar to section 110 to enable an application to the State Administrative Tribunal for an order to be made ex parte —

Sorry; I am preceding myself. I refer to the heading "Consent to medical research" on page 5 of the review, rather than recommendation 5. I will quote some passages on page 7 of the review that relate to submissions made by the Australian Medical Association WA and Hollywood Private Hospital.

It states —

The Australian Medical Association WA (AMA) recommends amendments to provisions which apply to the consent process for patients with short-term incapacity or severe illness, particularly in the emergency, intensive care and trauma contexts, who are incapable of consenting, or where time constraints and severe patient stress clearly make fully informed consent impractical; and amendments to show alternative consent processes for all other patients with disabilities—whether short or long-term, who lack capacity to consent in non-emergent situations. The amendments should apply to medical research procedures which include being part of a clinical trial, the administration of medication or the use of equipment or a device. Further the AMA emphasises that HRECs should be specifically authorised under the Act to be able to provide waiver of consent for studies performed in the emergency, trauma, and critical care environment.

Hollywood Private Hospital (HPH) submits that denying the opportunity of an individual to a new potentially beneficial therapy provided through a clinical trial can place them at a disadvantage. The HPH refers to the National Statement which indicates that people with cognitive impairment should not be excluded from research as a matter of course.

Those sentiments are, I think, broadly shared by sensible and compassionate people, but the statutory review also encompasses a range of other issues—in fact, some 80 or more further issues—that neither this bill nor its predecessor contemplates. I emphasise that because I think that, to some degree, this bill is misnamed, or at least the words of its title are in the wrong order, because it is not necessarily focused on the Guardianship and Administration Act but is really about medical research. To some degree the claim could be made that incapacitated people, through this bill, are effectively made a means to an end rather than being treated as an end in themselves. That might be a slightly uncharitable view to take, but I think it is a point worth emphasising because there seems to be unanimity around making the Guardianship and Administration Act 1990 more contemporary and more fit for purpose. That certainly was the Attorney General's view as he expressed it in 2018.

In 2018 I was honoured to participate in the Select Committee into Elder Abuse, along with the parliamentary secretary who has carriage of this bill in the chamber today. Throughout the course of our inquiries, the committee

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chair, my colleague Hon Nick Goiran, wrote to the Attorney General seeking advice as to the progress of enacting changes to the Guardianship and Administration Act 1990.

I quote some select passages from that document dated 24 April 2018 that are relevant. It states —

... the McGowan Government made an election commitment to expedite the enactment of amendments set out in the recommendations of the Statutory Review of the *Guardianship and Administration Act 1990*, and Cabinet approved the drafting of an amendment Bill in December last year.

He is referring to 2017 —

It is anticipated that the Amendment Bill will be introduced in the Spring session; —

Of 2018, presumably —

however, this will depend on drafting and Parliamentary priorities.

I make the point now that drafting and parliamentary priorities seem to have shifted somewhat over the course of the last five or six years, because that bill was not presented to this chamber in the previous Parliament or in this one. Members of the committee were not expecting that the Attorney General would agree to all 86 recommendations; this is effectively the discretion of any government to support some recommendations, amend others or just to discount the rest, but the Attorney General was pretty clear that he supported the bulk of them. From memory, he discounted between eight or nine, but the bulk of the 86 recommendations were supported, one or two of which found their way into the preceding bill dealt with by this chamber some three years ago.

I want to stop the time line a little in 2018, for in 2018, a problem of some kind emerged in the conduct of medical research in the Western Australian jurisdiction. I am not a medical practitioner nor am I a lawyer, but effectively, the issue was some interpretive ambiguity around whether incapacitated people could be made subjects in a clinical trial. Some would interpret the concept of medical treatment more broadly to include clinical trials; others were a little more compartmentalised in what constituted orthodox medical treatment versus clinical trial. That is probably a layperson's interpretation. What eventuated in 2018 were a series of directives from the Department of Health that effectively brought a halt to this practice. That was obviously cause for some concern. It precipitated some alarm about the future of cutting-edge research in the Western Australian jurisdiction and, to some degree I suppose, those concerns were well founded. Sometime in that 2018 period, a commitment was made by the Attorney General—I am not impugning any bad faith here—and the then Minister for Health, Roger Cook, to effectively deal with this ambiguity and provide a very clear lawful pathway for the practices that existed prior to 2018 being reinstituted. We heard little about that—I think; the record can always correct me—until 2020.

We all in this chamber understand what happened globally and in this jurisdiction in early 2020. I think the emergency declarations, the twin declarations made both under the Public Health Act and the Emergency Management Act, were first enlivened in the middle of March three years ago, if memory serves me correctly. This is not to be condescending to members who are new in this chamber, but the Parliament's response to that was, I think, very good, but we were navigating uncertainty. There was a uniform bipartisan commitment to put our political tribalism to one side and attempt together to navigate through what was known, knowable and unknown about COVID in the very, very early stages. That was done in a chamber that represented a greater political plurality than exists today. The original 2020 bill was very firmly predicated on being a COVID response—not entirely, but that was 80 per cent of its justification. I quote from the representing minister's second reading speech, the Leader of the House then as she is today, Hon Sue Ellery, who said —

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.

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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.

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The problem with the existing legislation —

She is talking about the 1990 act —

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

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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.

She went on further to say —

Although the McGowan government recognises the importance of implementing all the supported recommendations from the statutory review, —

Which I referred to earlier —

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.

To be fair to the Leader of the House then and today, that was a completely reasonable and sensible position to adopt, but it indicates that in the background are other issues. It is because in the early days we were navigating our way through a challenging COVID-19 environment, which we did not know the outcome of, that this chamber and the other house resolved to expedite decision-making and the legislative program. Indeed, it may not have been the first bill in this house to have been treated this way, but it was among the very first bills to be treated under the COVID-19 temporary order. It might interest members to know of the time constraints that applied then. They were 180 minutes for the second reading, 180 minutes for the Committee of the Whole, five minutes for the adoption of the report and 45 minutes for the third reading. Largely speaking, a bill of this magnitude, with this sort of ethical weight, was treated in a very rushed manner, but it was the best that this chamber could do. But underlying that agreement to deal with a substantial bill in an expedited manner was a degree of trust, and the application, where appropriate, of a precautionary principle. This was not the first and will not be the last bill that proposes some sort of novelty that does not include reference to guardrails or safeguards and the like. Outside the substance of the bill, as it was presented to us then, two guardrails were inserted, or applied, to ensure the wellbeing of incapacitated people who were subject to medical treatment without providing consent. The first guardrail deals with the matter that we are giving contemplation to now: the insertion of the sunset clause provisions. I will quote from *Hansard*, Thursday, 2 April 2020. Members will soon work out why I put special emphasis on this. It states —

Postponed clause 2: Commencement —

Resumed from an earlier stage of the sitting.

Hon MICHAEL MISCHIN: I move —

Page 2, lines 7 and 8 — To delete the lines and substitute — receives the Royal Assent (assent day);

- (b) sections 12A and 14 on the day after the period of 4 years beginning on the day after assent day;
- (c) the rest of the Act on the day after assent day.

The effect of this amendment will be that new section 12A will come into effect four years after the amendments come into operation and that will repeal proposed section 110ZS and also bring into effect the transitional provisions to protect the research that is currently going on.

This was the bit that dealt with the sunset clauses that we are attempting to pull out today. Then Hon Sue Ellery said —

I concur with the description provided by the honourable member. As I indicated to the chamber, this is part of a package of things that have been agreed to give practical effect to a sunset clause, and the government is happy to support it.

What does that indicate? It indicates that the sunset clause was discussed behind the chair and was not opposed. It was Hon Michael Mischin, the then shadow Attorney General, who moved it. It was supported by the crossbench and the government. "Not making the best the enemy of the good" might have been a way of describing the implementation of a sunset clause.

Another thing that was done—very strangely, as it happens—in the course of the treatment of bills in this house was that after the third reading, the bill was referred to the Standing Committee on Legislation. The committee gave the bill its contemplation despite the fact that the bill had already passed the Parliament. I understand that that very unusual scenario is not necessarily unprecedented, but it is a very, very unusual scenario. But what is more unusual, over the course of the last two years, is the degree to which bills have not been referred to the Standing Committee on Legislation at all.

It is worthwhile identifying that the forty-eighth report of the Standing Committee on Legislation regarding the Guardianship and Administration Amendment (Medical Research) Bill 2020 was a very good, solid piece of research. I have looked for a report of similar quality and gravity from that committee in the last two years, but when I went

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to the website, I did not find anything. I am sure we will refer to that matter again at some stage, but I want to very briefly refer to an element contained within that report on page 22.

Members might recall that the bill was effectively rushed through this chamber on the basis of the need for an expedited COVID-19 response. We could not leave anyone behind. I want to underscore exactly the right principle for the chamber to adopt. When the report was handed down in November, what had the committee found during its deliberations through September and October? It found that not much of that went on. No individual patient had been enrolled in any kind of trial related to COVID-19 basically because the statutory forms had not been drafted. If I cannot critique the government for the motivation, what is entirely appropriate for me to do is to critique the government's application or lack of consistency because that introduces in my mind a measure of cynicism, which I think generally is healthy but maybe somewhat unhelpful or uncomfortable for the government.

It is also worth reflecting that the substance of the committee's report endorsed one of the key tranches of this bill, which is to repeal the sunset provisions. I do not want that to go unremarked; I do not necessarily want to cherrypick from this report either. But this goes to the element of trust that is required at some level for legislation to be scrutinised, fairly dispassionately and rigorously in this chamber, and that what the government tells us is the purpose for a bill is actually going to be given effect to. At that very early stage, within four to six months of that bill initially passing this house, none of that had transpired. Embedded in the bill was a guardrail of some kind, which was a commitment to review the act itself within 12 months. That deadline was missed, regrettably. I understand that that review was at least 12 months late, and I will get to the timing of that later.

Actually, I will refer to that final review, which was an interesting document, a good document, and I encourage members who take an interest in this bill to read the final report conducted by the Department of Justice entitled *Review of the Guardianship and Administration Amendment (Medical Research) Act 2020 (WA): final report*, which, if memory serves, was tabled on the very same day that the parliamentary secretary introduced and moved the first and second readings of this bill. This is a message to people outside this chamber: it would have been helpful for that report to be tabled at an earlier opportunity, and I believe there was an earlier opportunity because the very helpful and capable staff at the Attorney General—in late October last year. So some months went past when there were opportunities to table, but they were not taken up, I think, sadly, because that document is intimately related to this bill and drives a series of questions that the parliamentary secretary or his advisers might be in a position to answer.

Hon Matthew Swinbourn: Sorry, what was that?

Hon TJORN SIBMA: The final report of the Department of Justice. There are some key bits of information embedded in it that relate to this bill.

Hon Matthew Swinbourn: That may be a matter best left for committee.

Hon TJORN SIBMA: Yes, sure—in committee. That is fine; we will get there.

I mentioned a note of cynicism, and if I was not cynical enough, my cynicism was elevated quite substantially when in preparation for this debate, I read a grievance made on 24 November 2022 by a person for whom I have large personal regard, the member for Mount Lawley. I want to quote some passages from that, not selectively, because it is so very clearly expressed. They are passages that indicate a serious degree of misdirection, misrepresentation and bad faith around the history of this bill, the magnitude of the issues addressed and the enormous magnitude of the issues that are not addressed, and I reflect on that 2015 statutory review. I will allow members to make up their own minds and to form a view about whether my cynicism is justified in these circumstances.

I quote the grievance from the member for Mount Lawley —

... I would like to highlight the problem. When this McGowan Labor government introduced world leading amendments to the Guardianship and Administration Act at the height of the COVID pandemic in 2020 to facilitate more effective medical research, we amended section 110ZS, which provided for urgent medical research without consent within the Guardianship and Administration Act.

Already in that one long sentence there have been commissions of errors of fact. What was world leading? That is arguable. We were not at the height of the pandemic in early April 2020; we were at the beginning of it. The member goes on, and this is more specific. That was marginal compared with what comes next. I quote —

My grievance this morning concerns the unfortunate behaviour of Hon Nick Goiran in the upper house and his insistence on imposing a sunset clause on what is otherwise widely commended legislation. My concern and that of the legal and medical experts who have raised this matter with me is that the operation of the sunset clause will stand in the way of this groundbreaking, world-leading medical research. My grievance is that members of the Liberal Party who like to say that they support our health system behave in a way that is entirely inconsistent with that when people like Hon Nick Goiran place barriers in the path

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of medical research that makes it harder for our expert clinicians, academics and medical researchers to do their work.

That is a fundamental mistruth, a fundamental misrepresentation of the facts, utterly, not to advance the interests of medical research in Western Australia, not to advance the interests of incapacitated people subject to the act, but to score cheap political points; that is it. Grievances, particularly when they are brought to the other house's attention by a government member, are not done without the foreknowledge and forewarning of the responding minister. They never have been and never will be, certainly not under this government.

The Attorney General then said in reply —

Back in 2015, the Department of the Attorney General conducted a statutory review of the Guardianship and Administration Act 1990 to assess the operation and effectiveness of the amendments made by the Acts Amendment (Consent to Medical Treatment) Act 2008. Having consulted the Public Advocate, the Public Trustee, the Department of Health and over 163 government and non-government agencies, health services and medical ethics committees, the statutory review found strong support to amend the guardianship act to allow consent to medical research treatment for people temporarily or permanently incapacitated under guardianship orders.

The Attorney General forgot to mention that there were a range of other recommendations, in the dozens, that came out of that statutory review that have not seen the light of day, despite the fact that he advised the house that they were supported and the bill was being drafted. I think it was drafted back in 2017. But this is where the government doubles down on the misrepresentation of the passage of that bill through this house done on good faith three years ago. The Attorney General continues —

As the member for Mount Lawley noted, the sunset clause was included in the bill and is due to take effect on 8 April 2024.

I think it is worth bearing in mind that the alleged offence we are trying to pull back will not really become operative until next year, but I will leave that to where it is. The Attorney General continues —

As the member noted, this was included at the insistence of Hon Nick Goiran in the upper house, and, as I said to Professor Danny Fatovich at the time, we cannot let perfect get in the way of good. We had to get the bill through. Politics is about the art of what is possible. At that stage back in 2019, Labor's views did not always carry in the upper house—such is not the case today. As I said, the bill contained a review clause that the other chamber, at the behest of Hon Nick Goiran, changed into a sunset clause. Under that clause, I am required to review the operation and effectiveness of the medical research amendments in accordance, as the member for Mount Lawley said, with section 110ZZE of the Guardian and Administration Act 1990. As the member outlined, the review is ... representatives ...

And he goes on. He also goes on to say —

I expect that the final report will soon be presented for my consideration.

In fact, it had been. It had been in his office for a month. Again, the Attorney would have done a lot better by reading the *Hansard* of this place more closely and would have been wise not to have fully endorsed the accusation of this sort of obstructive response to not only the bill, but medical research more generally, and laid it at the feet of one member. That is not how this chamber operates and it is not how it has ever operated—never.

I have an absolute degree of sympathy for this. I say this not to wish the Attorney General any ill—certainly not—or to trivialise his own health challenges that he has been very candid about, but he said —

I have a personal interest in this matter having been the beneficiary of medical research when I was diagnosed with T-cell lymphoma back in the day. Earlier in my parliamentary career, I was a bit lost in Western Australia because no research had been done into that rather obscure or rare disease.

I cannot fault him at all. We are all, to a degree, beneficiaries of medical research. The fact that we survive our childhoods beyond the age of five is largely testament to medical research. The fact that my daughter was alive five or six weeks after she was born and treated in hospital with an infection is testament to medical research. I was the subject of clinical trials during my childhood. But there is a difference between that and the claim that the Attorney General made, particularly in his own personal case, because he was able to provide consent. The only reason that this chamber was a little bit guarded—moderately guarded, I think, would be better to say—in the treatment of the bill in 2020, was that it was dealing with incapacitated people who could not provide consent. When we deal with bills in this chamber, be it this bill or any other bill, it is actually worth trying to put in the effort to read the bill and absorb as much of it as we can and be a little more discriminating rather than accepting at face value the claims made by anybody, including, it has to be said, the Attorney General. Frankly, that is most unfortunate.

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The bill that we are dealing with today implies a number of things. One of the principal claims is that this looming cliff, represented by the sunset clauses, is such a challenging and dangerous precipice that almost all medical research in Western Australia is jeopardised. That is the kind of claim that I was interested to understand a bit more about when I was briefed, quite helpfully, on this bill. Being as critical of the government as I am, I want to take the opportunity to underscore the professionalism of the advisers from the Attorney's office and the departments concerned. I wanted to understand, for example, the financial quantum of medical research funding that will be lost if we do not deal with this bill in the way that it has been presented to us. I will give this document to Hansard later. I asked —

Is it possible to quantify, in research dollars, the purported loss on part of WA given the sunset clause and associated restrictions/can you hypothesise the research money lost as a result of the looming sunset clause in WA?

Alternatively, how many lines of research have been rejected or not progressed because of the uncertainty of the sunset clause?

The answer that I received was not granular. It states —

The Department of Health advises that the Federal government health and medical research budget estimate for 2021–22 was \$1.769 billion.

Western Australia has 10.4% of Australia's population ... —

I will summarise this. This is the important thing —

It is not possible to know how many federal grant applications from WA will involve the represented population, however, if we assume that it is 1%, then the potential income under threat would be \$18.4 million over a ten-year period.

Further, to another similar question, it states —

The Department of Health advises that the impact of the sunset clause on missed research opportunities cannot be quantified accurately. Typically, the decision to develop or proceed a research idea is made by the lead researcher during preliminary feasibility assessments.

These assessments occur informally and are often not documented. The intentions of individual researchers cannot be determined and there are no requirements for research ideas and/or plans to be reported.

I understand some of that, and I am prepared to accept that is a pretty candid response to a difficult question to answer. However, when the claim is made again and again that the sunset clauses are such a great inhibitor to medical research in Western Australia that they need to be repealed now has not been substantiated. As a member of the opposition, and as a private member, I find that inherently disappointing. We are dealing with clinical research and issues that require quantification. We are not here to accept assertions and take them completely at face value, which is what is being done here. To have an informed debate on medical research, I would like to be able to say that medical research in Western Australia represents X amount of gross state product and that we have an opportunity to double or triple research funding by, for example, focusing on research on these particular areas. I think medical research universally and in a bipartisan way is enthusiastically gripped by members of this chamber, and we have a function next Tuesday evening to that effect. But I am disappointed—I do not mean this as a negative reflection on the quality of the staff or their advice—that, generally, the best the government can do is substantiate the principal argument here about the danger of this sunset clause, which is this great impediment. That is inherently disappointing.

Another issue related to that is that if the government cannot provide advice on the number of research projects that cannot be proceeded with or the number of current research projects that have had to be terminated or the dollar value or the missed investment, what kind of quantum are we talking about? How many people, for instance, have been affected by the 2020 version of this bill—the current act? This is where I think things get interesting. Again, I commend the good work of the advisers in the Attorney's office who have provided these answers to my inquiries. Presently, 115 patients are captured under the existing bill. Of those 115, 100 have provided supported decision-maker consent and 15 did not provide that consent. I understand that the sunset clauses relate specifically to urgently dealing with the 15 people without consent. Over the course of the operation of the bill, some 220 or so people have been managed under the bill, but let us concentrate just on those 115.

If I were to read the government's argument superficially, I would assume that the future of medical research in Western Australia is carried on the shoulders of those 100 or so patients, to the exclusion of everybody else. That is one way of trying to apply the government's argument. That is not to say that the research that applies to those people and that the clinical trials in which those people participated are not important; that is not the argument I am making at all. However, if someone read the argument that medical research in Western Australia is going to be jeopardised if we do not get this bill—which, among other things, takes out or appeals that nasty sunset clause—through today, they would ask "Well, actually, how many people are we talking about who participate in this act?"

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It is 115 people. It is effectively being said that this group of 115 people is taking upon their shoulders, some with assisted consent and some with none at all, almost the entire burden of medical research in Western Australia.

I know that is not what the parliamentary secretary is saying. However, if the risk of the looming implosion of medical research is to actually be justified, and this is the claim that the government is making not only through this bill—it was done in a more moderate way through this bill—but in taking the member for Mount Lawley's grievance and the Attorney General's response at their word, that is the only conclusion to be drawn: there is something quite catastrophically wrong in the way that we deal with these people, not as ends in themselves, but as means to some research end.

I think this is a point which we can be a bit more nuanced about. I am not assuming, nor am I arguing the case, that the people we are talking about are not also potentially beneficiaries from these clinical trials. I am not arguing that they should have potentially profitable, fruitful cutting-edge treatment denied to them by virtue of their inability to voluntarily express consent. I am not saying that at all. However, this bill really does not deal in a compassionate way with, nor does not give primacy to—I think is a better way of expressing it—the needs and rights of the people we are talking about. What we are talking about is the convenience or inconveniencing of medical researchers. That is the principal conclusion that I would draw. That is what this bill is attempting to do. We should not argue for the impediment of medical researchers, but I think it is also very important to underscore the need to balance values here. At the very least, there needs to be the rights of protection, to address and review for these people. That is something worthy of the chamber's consideration.

I might come back in a little bit to where I started to address, very briefly, the potential for adverse outcomes that is inherent in any form of research. Let us recall the context in which this bill was dealt with in 2020. Its grounding as a COVID-19 response was unambiguous. Having read the final report and what was found in late 2020 by the excellent work of the Standing Committee on Legislation, I wanted to understand whether or not there was any light to shine on whether this bill had been a useful COVID-19 response measure.

This answer gives some insight as to probably why WA Health has not answered any of my questions about medical research generally—funding pools, opportunity costs and the like. It stated —

The Department of Health advises that since April 2020, 13 projects involving a novel treatment for COVID-19 have been conducted at WA health sites. None of these projects involved incapacitated adults and therefore did not make use of the provisions of Part 9E of the GAA.

Within WA health, there is no mechanism in place to determine if any projects examining novel treatments for COVI D-19 were conducted in their entirety at private and academic centres.

I understand that that is a knowledge gap. It goes on to state —

The Office of the Public Advocate has advised that it is aware of one case where a represented person appeared to participate in research under the urgent provisions relating to medical research at Royal Perth Hospital, but in relation to substance abuse rather than COVID 19 treatment.

Of the pool of 220 individuals who were dealt with under the auspices of this act, maybe one received a form of COVID-19—related treatment. That was a large justification for the act being presented to the chamber in the way that it was. It was dealt with under the expedited temporary order of this chamber, which gets to the heart of intent and follow up. That informs my now somewhat increasingly cynical view of whether or not I should just take second reading speeches or explanatory memoranda at face value. I know I cannot take grievance motions at face value. They are always a form of political artifice.

It was right for this house, and not just one individual, to be a little cautious and circumspect about how we enrolled incapacitated people—including people who cannot provide consent—in clinical trials. I think it is a reasonable precaution, not suspicion, to adopt. I think there is a lesson to be learnt, if not some humble pie to be eaten. It will not be eaten by any member of this government. There is at least a lesson to be learnt about the treatment of legislation in this house more generally. Thanks to the bipartisan composition of that legislation committee, it did its job and did it very well.

It is a dimension of our parliamentary life that we have seem to have forgotten about these last two years. I think we forget about it and do not use it at our peril. The issues I have gone over are largely historic. I will put very clearly on the record that the opposition supports what the parliamentary secretary is attempting to do here. However, bills like this are not without consequence, or moral or ethical input. There are other bills that will be, frankly, very speedily presented or debated in this chamber over the next few weeks. Those bills are far more comprehensive than this one. I think there are probably some constructive opportunities for the Standing Committee on Legislation to assist the government in understanding the implications of its own bills, and perhaps providing some guidance when it comes to the execution of regulations and the drafting of statutory instruments—which will certainly be a consequence of the Criminal Law (Mental Impairment) Bill, a great body of work. I encourage the government

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to adopt a measure of humility. That kind of bill is one that I would expect to be referred to the Standing Committee on Legislation. I hope that that committee is fully utilised, or at least utilised in part a bit more over the next two years than it has been over the course of the last two years, because that committee did this chamber a service in fleshing out some of the attributes of the 2020 amendment bill that we dealt with three years ago.

There is no doubt, parliamentary secretary, that there is additional territory to cover in committee. I understand that other members wish to speak on the Guardianship and Administration Amendment (Medical Research) Bill 2023, but I want to underscore the point that a bill such as this deserves to be treated in its full historical context. I look forward to the parliamentary secretary's response.

HON NICK GOIRAN (South Metropolitan) [3.00 pm]: The Guardianship and Administration Amendment (Medical Research) Bill 2023 will be of interest to a person if they are a medical or legal practitioner and it should be of interest to any Western Australian, the reason being that at the very heart of this bill is the principle of informed consent and how it is applied in circumstances in which a Western Australian finds themselves incapacitated for either a short or extended period.

The bill presently before us will amend the Guardianship and Administration Act 1990. The debate on that legislation took place in 1989. Over the course of my preparation for this debate, I had cause to look back at the somewhat now ancient format of *Hansard* at that time to note the remarks made in the other place during consideration of the Guardianship and Administration Bill, as it was entitled. The following remarks were made in the other place—for the benefit of Hansard, I refer to page 2034—by Mr Wilson, the then Minister for Health —

Under the current law the emphasis of concern is the need to protect property while making no adequate provision for actually protecting the ordinary needs of the individual. The Bill will provide for this.

This Bill replaces an over-emphasis of concern for property with a recognition of personal needs as well as the safeguard of property. The proposals will have far-reaching results affecting a wide cross-section of the community. It will be available to all persons over the age of 18 years who unfortunately are unable, for reason of mental disability, to manage their own affairs and who need the protection of a caring guardian with their welfare at heart.

His speech concludes —

This Government recognises the predicament many elderly, mentally ill and intellectually disabled people are in; it is providing a mechanism for assisting them in a manner which least restricts a person's civil liberties.

We can see that the objective at the time was to replace the overemphasis on and concern about property with the recognition that we need to deal with people's personal needs as well as safeguard property. It was expressly said to be targeting all persons who, unfortunately, are unable to manage their own affairs and who need the protection of a caring guardian with their welfare at heart. Importantly, the act was designed to assist people with impaired capacity in a manner that would least restrict their civil liberties. The question that is worth reflecting on is: was it envisaged that just over 30 years later, this act would extend to the provision of medical research without consent—not medical treatment without consent, but medical research without consent? Was that envisaged some 30 years ago when the Guardianship and Administration Bill was first debated? Moreover, given that the decision to be enrolled in medical research cannot be made by the person because they are incapacitated, was it envisaged at the time that the decision would be made by a researcher who wants to enrol the person or a category of persons in medical research, which will be broadened by the bill presently before the house? Indeed, was it envisaged that researchers and independent medical practitioners would become the caring guardian of people who are unable to make reasonable judgements?

During the debate this afternoon on the Guardianship and Administration Amendment (Medical Research) Bill 2023, it is important that we keep top of mind that the act was implemented to recognise the importance of preserving the rights of incapacitated persons; the statute was never designed to preserve the noble desires of researchers. As Hon Tjorn Sibma eloquently put to us this afternoon, we are all the beneficiaries of medical research in Western Australia. I think we can agree that the desires of those researchers are noble, but their noble desires cannot somehow now trump the rights of the incapacitated person. That is the very heart of the debate that we will have this afternoon, as we did in 2020 when the earlier iteration of this amending bill was put before us.

I ask members to contemplate whether allowing medical research without consent respects and preserves the right to informed consent. Article 17 of the Convention on the Rights of Persons with Disabilities states —

Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.

The right of informed consent is not to be taken lightly. The entire notion of informed consent for medical research and, if you like, medical experimentation has very dark origins. I draw members' attention to an academic article

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published in 2021 in *The Ochsner Journal* titled "A Modern History of Informed Consent and the Role of Key Information" in which the following remarks are made —

The concept of informed consent has a relatively short history, beginning with a series of 4 judicial decisions in the early 20th century that laid the foundation for the principle of patient autonomy.

The authors discuss four legal decisions in particular. However, later on they say —

... the concept of informed consent in human subjects research began to emerge in parallel as a consequence of the investigation of Nazi war crimes at the end of World War II.

In preparation for this speech, I questioned whether I should bring this to members' attention, because it is a phenomenon of modern debate that if anyone mentions the "N" word and the events that took place in Germany, that somehow neutralises the debate and nothing further can be discussed about such matters. I ask members that rather than do that, they should contemplate for a moment that the principle of informed consent has these dark origins. The article further states —

On August 20, 1947, the trial of 23 physicians and bureaucrats charged with crimes against humanity and war crimes for medical experiments conducted on concentration camp inmates concluded in Nuremberg, Germany. The verdict of the International Military Tribunal, a trio of American judges empowered under international law adopted by the Allied powers, set forth a series of 10 basic rules for the conduct of human experiments that has become known as the Nuremberg Code. The Nuremberg Code represents the first explicit attempt to regulate the ethical conduct of research experiments with human subjects and is notable for the emphasis it places on voluntary consent. A section of the ruling entitled "Permissible Medical Experiments" states, "...certain basic principles must be observed in order to satisfy moral, ethical and legal concepts" in human subjects research. The first of these concepts is the voluntary consent of the human subject. In further statements, the court defined the specific context and meaning for this concept:

This means that the person...should have sufficient knowledge and comprehension of the elements of the subject matter involved, as to enable him to make an understanding and enlightened decision. This latter element requires that, before the acceptance of an affirmative decision by the experimental subject, there should be made known to him the nature, duration, and purpose of the experiment; the method and means by which it is to be conducted; all inconveniences and hazards reasonably to be expected; and the effects upon his health or person, which may possibly come from his participation in the experiment.

I would love to spend more time considering the history of the principle of informed consent if we had more time this afternoon. Suffice to say, I trust that members can see how dark humanity can get when it comes to the notion of research and experimentation on individuals, and why it is right that all of us—all 36 members of this chamber—staunchly defend the principle of informed consent.

In that context, I am grateful to Hon Tjorn Sibma, who earlier this afternoon reminded us of the comments of the Attorney General in the other place late last year, who seemingly quite sincerely, in accordance with the record, reflected on the fact that he had participated in a medical trial. I associate myself with the comments about and sympathies extended by Hon Tjorn Sibma to the Attorney General on his health at that time, but I make this observation: the Attorney General enrolled in that trial, as was his right. I am glad to hear that he had a positive experience. The point is that he voluntarily consented to participate in that trial, as he was quite entitled to do, and has received some benefits. Perhaps others also received benefits as a result of it. That situation is not at the heart of the debate before us this afternoon. I am unaware of anyone who has any objection to or problem with any person with capacity in Western Australia putting up their hand freely, voluntarily and in an informed fashion and enrolling as a medical research subject. That is not the heart of the debate here. I am also grateful to Hon Tjorn Sibma for quite correctly exposing the entirely confused, confusing and unreliable speech delivered, in this case, by the member for Mount Lawley. Until that speech, I must say that I thought that the honourable member from the other place was quite a decent chap.

Hon Matthew Swinbourn: He is a decent chap. Perhaps do not reflect on his character in that way.

Hon NICK GOIRAN: As I said, prior to that speech, I shared that view.

Hon Matthew Swinbourn: You might take issue with what he said, but to reflect on him by suggesting that he is not a decent chap —

Hon Tjorn Sibma: I think you are pre-empting, parliamentary secretary.

Hon NICK GOIRAN: Hold your horses, parliamentary secretary, because what I am about to say is that a decent chap will recognise the error of their way and then correct the record. That has not yet happened. There will be an opportunity, because as the hardworking parliamentary secretary will be aware, in this instance the bill—correct me if I am wrong—was introduced in the Legislative Council.

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Withdrawal of Remark

The ACTING PRESIDENT (Hon Dr Brian Walker): Order, member. On reflection on the debate so far, I am of the opinion that reflecting on the personal qualities of a member of this place or the other place is probably inappropriate. I ask you to reconsider those words.

Hon NICK GOIRAN: Okay. To be clear, Acting President, I had said that I thought that he was a good chap. I think that is a positive reflection of the individual. If I am not to reflect on him in a positive fashion and say he is a good chap, I am quite happy to withdraw that remark. I will simply make the observation that if I cannot say that he is a good chap, I will leave it for others to determine what kind of a chap he is! I say in all sincerity, Acting President, that there will be an opportunity for the honourable member in the other place to reflect on the comments made by Hon Tjorn Sibma, who quite correctly corrected the record.

Debate Resumed

Hon NICK GOIRAN: I note that in his speech on 24 November last year, the member for Mount Lawley referred to an article in the *Tasman Medical Journal*. He was quite entitled to do that, but in his enthusiasm to do so, I draw to his attention that there was also a WA Mental Health Commission submission that he might have liked to reflect on, which raised concerns over the inclusion of placebos. I think he might be the Parliamentary Secretary to the Minister for Mental Health.

Hon Matthew Swinbourn: Yes.

Hon NICK GOIRAN: One would think that the Parliamentary Secretary to the Minister for Mental Health would have some expertise in the submission put forward by the WA Mental Health Commission. Perhaps before the honourable member does his speech in the other place, he might like to read that and note its concerns. Meanwhile, the so-called grievance put up by the member for Mount Lawley in the other place in November last year was responded to in a confused, confusing and unreliable fashion by the Attorney General, who compounded the error made by the member in the other place. Ironically, he completely ignored that the Attorney General breached the law of Western Australia at that time. The member for Mount Lawley was quite happy to go into the other place and put up a grievance, falsely suggesting that I had done something—the record now reflects that that was false; Hon Tjorn Sibma very eloquently set out the correct chronology of events and correctly identified the individuals who moved sunset clauses and the like—but meanwhile he had no grievance whatsoever with the Attorney General's complete breach of the law of Western Australia. Why? Of course, we have the benefit of a summary report to Parliament provided by the Department of Health, as I understand it, and I anticipate that we will spend some time during Committee of the Whole House looking at that report, the report of the Standing Committee on Legislation, and the statutory review report that was belatedly provided by the Attorney General, amongst other things.

I think it is important, when correcting the record, to address the concerns of the member for Mount Lawley and the Attorney General—that somehow the inclusion of a sunset clause was some kind of heinous offence. For those who were not here at the time, in 2020 the bill we are talking about was declared urgent and was rammed through both houses of Parliament in less than 24 hours. This was a bill that dealt with the question of whether Western Australians should be enrolled without consent in medical research—not medical treatment, but medical research—and it was rammed through both houses of Parliament in less than 24 hours. That is the history.

Indeed, on Wednesday 1 April 2020, the bill was introduced and passed in the other place, and then introduced into this place—all in one day. Members should consider that for a moment. Two days earlier I participated in a briefing and we were being urged by eminent legal mind Hon Wayne Martin, QC, to support the bill. We were being told that we should support the bill. Members should keep in mind that this was two days before the bill was introduced and passed in the other place and then introduced into this place. It went through the other chamber and then came in here, all in one day. Two days before that, we were being told in a briefing, "You really should support this bill." The bill we were being told about on the Monday was version 10; by the time the bill was introduced into this place on the Wednesday, two days later, it was version 21. On the Monday we were being told, including by Hon Wayne Martin, "You must support this bill, which is going to allow for medical research to be conducted on Western Australians without their consent"; by the time we debated the bill on the Wednesday, it was at least 11 versions later. It was rammed through the Legislative Council on Thursday, 2 April.

By way of context, members should also keep in mind that this happened despite the fact that the bill I am referring to sought to implement a key reform that was recommended against in the statutory review of the Guardianship and Administration Act 1990. That review was conducted by the government and the department and tabled in December 2015. It expressly said, "Don't do this", but the government did it anyway. Fair-minded members can easily imagine that a member of the opposition and the entire crossbench at the time might say, "Hang about; we want to take another look at this. Let's get this right. You're asking us to pass a bill through both houses of Parliament within 24 hours. The versions are changing more quickly than I've had hot breakfasts, and now it is actually implementing a recommendation that the statutory review said not to do."

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Indeed, I note that the statutory review made 86 recommendations and the 2020 bill was implementing only two of them—recommendations 6 and 7. The statutory review specifically recommended —

Health professionals acting under the urgent provisions in sections 110ZI and 110ZIA will not be permitted to make a decision on behalf of a represented person for that person to participate in medical research ...

Concerns were raised about the lack of penalties if reasonable steps were not taken to determine whether an advance health directive or an enduring power of guardianship was in place. There were also concerns about whether it was an appropriate way of dealing with conducting medical research on the most vulnerable cohort of our society—those with impaired decision-making capacity. That is the actual context, rather than the confused, confusing and entirely unreliable recollection of events from the member for Mount Lawley and the Attorney General.

I might add, for the record, that it was a former honourable member of this place, Hon Aaron Stonehouse, former member for South Metropolitan Region, who first suggested that a sunset clause be included in the legislation. At a later stage, the then shadow Attorney General, Hon Michael Mischin, moved that the sunset clause be put in. I say all that simply to point out that if the member for Mount Lawley and the Attorney General want to somehow blame me for the fact that there is a sunset clause in this bill, so be it. To this day I will quite proudly say that we supported the inclusion of the sunset clause. It was an entirely appropriate thing to do. But if those members are going to have a crack at me, they should make sure, at the very least, that they get some of the basic facts right; it is really not that difficult, but it would require a capacity to read, and as I have said previously, I know that that is not the government's strong point.

Here we are, three years later, and we have the Guardianship and Administration Amendment (Medical Research) Bill 2023 before us—which I might add, in passing, has my support. Here is the great irony —

Hon Matthew Swinbourn: After all that! Sorry; I'm not having a go.

Hon NICK GOIRAN: Well, the parliamentary secretary is quite right. It is unbelievable, is it not? In 2020 the previous bill also had my support. Is it not incredible that members in the other place would concoct that narrative to absolutely no purpose whatsoever? The really offensive part of it was the suggestion by the member for Mount Lawley that Liberal members are somehow anti-medical research, and all the rest of it. Where does he come up with this stuff? It is not that hard; he should just read the *Hansard* transcript and he will actually get a faithful recollection of events.

As I said, I do not quibble at all about the fact that there was a sunset clause put in, and I know—I think Hon Tjorn Sibma already said this in his contribution, but I was away on urgent parliamentary business—that the government did not oppose it. I cannot see anything on the record to say that there was a whole heap of noes in respect of the sunset clause. It is a bit rich for members in the other place to carry on in the way they did in November last year. In fact, the record reflects that Hon Sue Ellery, who had carriage of that bill on behalf of the government at the time, said that the government was happy to support the sunset clause. Right. Well, no doubt there will be a speech about that from the member for Mount Lawley as well.

Let us also consider, in that context, that the matter was then referred to the Standing Committee on Legislation; if I recall correctly, Hon Dr Sally Talbot was chair at the time. The two of us were on that committee for a good four years, and we had the opportunity to consider this bill after it had actually been passed. The Standing Committee on Legislation reported on 25 November 2020 and made 86 recommendations. Again, the member for Mount Lawley might like to read that and he might note that the committee found that the sunset clause could be repealed. Who was on that committee? I was one of the members of the committee who suggested that the sunset clause could be repealed. It was unanimous. In that committee report, if the member can spend some moments to read that and the accompanying submissions, he will see that a submission was received in favour of keeping the sunset clause. Who would be so bold in Western Australia as to suggest that the sunset clause should be maintained? The WA Mental Health Commission. The WA Mental Health Commission put a submission to the committee in favour of keeping the sunset clause. Maybe the Parliamentary Secretary to the Minister for Mental Health might like to reflect on that. The commission expressed concerns over the inclusion of a placebo in the definition of medical research, and how to use a placebo in the candidate's best interest. It stated that more comprehensive steps need to be taken by independent medical practitioners when considering a candidate's best wishes, and that religious cultural beliefs and values were to be considered. It welcomed the sunset clause as a safeguard against the misuse of section 110ZS. Its remaining concerns revolved around the impact on the ability to obtain funding for medical research projects. As Hon Tjorn Sibma identified, it would be good if we could be provided with some kind of granular detail in respect of that matter. I maintain that it was absolutely the best tool available to the opposition, the crossbench and indeed the entire Legislative Council as the house of review when confronted with an urgent bill, which would have an impact on vulnerable Western Australians and restrict the right to informed consent, being rammed through in less than 24 hours. It involved limited debate, with guillotines going left, right and centre. It included provisions contrary to recommendation 6.2 of the 2015 statutory review of the act. If, in all those circumstances, members of the government still want to try to make an intelligent, unconfused and reliable argument about why there should never have been a sunset clause in the first place, go for it. I will listen with interest.

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Meanwhile, a review was to be conducted pursuant to section 110ZZE of the Guardianship and Administration Act. That report was due to be tabled before each house of Parliament by 7 April 2022. Perhaps in the parliamentary secretary's reply or during debate on clause 1 he could let us know the date that the review report was tabled in each house of Parliament. I can already tell the parliamentary secretary that it was after 7 April 2022. The date is late, but if he can identify the date that it was tabled in each house of Parliament, not just in one house but each house, that would be excellent. Meanwhile, on 17 August 2021 I asked what was happening with this review. The response from the Attorney General to my question without notice 520 was that the review was to commence as soon as possible after 7 April 2021. He acknowledged that the report was to be tabled on 7 April 2022. As at 17 August 2021, the Attorney General of Western Australia confirmed that he was aware that he was under an obligation to table a report by 7 April 2022. There can be no defence that he was ignorant of his responsibility. His answer in Parliament confirmed that he was required to do it by 7 April 2022. He acknowledged it himself.

Of course, trying to assist the Attorney General as best as I can from time to time, on 1 September 2021, I asked follow-up question without notice 605 regarding the review, which was supposed to have commenced on 7 April. The response indicated that the project reference group to develop a review plan was established on 3 August 2021, interestingly, almost four months after the review was to commence. Apparently, this review plan was to be endorsed by an evaluation and review steering committee comprising representatives from the Department of Justice: Corrective Services, Court and Tribunal Services, Office of the Commissioner for Victims of Crime and the Western Australian Office of Crime Statistics and Research. Also, very interestingly, the Attorney General had not yet been briefed on the review, despite the fact that it was five months after the review was due to commence. Nevertheless, in September 2021, I left it there, noting that the Attorney General was well aware that he was under a legal obligation under the law of Western Australia to table the review report in April of the following year. Of course, April came and went. There was no sign of this report. Question without notice 1280 on 29 November 2022 was asked by me to the parliamentary secretary representing the Attorney General. I was told that the Attorney General said that the review would be tabled as soon as possible. That was yet another entirely unacceptable response to a question highlighting that the law of Western Australia had been broken. This is really just a cavalier approach to whether we will comply with the law of Western Australia by the McGowan government. That is why members will be aware that there is a motion standing in my name on the notice paper dealing with this particular issuethat is, the breach of law by the Attorney General of Western Australia. When the response is provided by the parliamentary secretary, we will see whether the breach has ended—that is, whether the report has been tabled in each house of Parliament. We know that it certainly was not done by 7 April 2022. We will find out which date it occurred in both houses.

In concluding my remarks, I want to address a couple of final concerns. As I said earlier, the bill before us has my support. Firstly, it essentially seeks to remove the sunset clause so that the operation of the scheme can continue; and, secondly, it seeks to widen the scope of the definition, if I remember correctly, of "lead researcher". Those two things have my support. However, my primary concern is that we will move from a very substantial oversight regime to a regime that seems to have no oversight. Briefly, by way of explanation, members will be aware that due to all the concerns that I just outlined—that 24-hour ramming of the bill through the Parliament in circumstances when we are talking about Western Australians being enrolled in medical research without their consent—the Parliament decided that a dual oversight mechanism would be put in place. Not only would the Standing Committee on Legislation be required to look into this matter after the passage of the bill, oversight mechanism number one, but there would also be the statutory review process to which I referred earlier. We had two levels of oversight on this matter: we had Parliament performing a function and we had executive government performing a function. After this bill passes, what oversight will be provided? Will any express oversight be provided by the Parliament of Western Australia with respect to this scheme that will continue to see Western Australians enrolled in medical research without their consent? I hasten to say at this point that the concern that I have, if members are getting any impression that I have a concern, revolves around the definition of "medical research". If "medical research" is defined or performed in the sense of some observational activities or what I might describe as non-invasive measures, I do not have a problem with that. If I recall correctly, there was a comment in the statutory reviewthat late document that was provided to the effect that observational or non-invasive activities probably should not even be captured in the definition of "medical research". That is an interesting debate in itself. The point being that if it is of that non-invasive type of activity, I really have no problem with that. I still think that every best endeavour should always be made by medical practitioners and researchers. If they cannot get the consent of the primary research subject, they must make every best endeavour to obtain it from the substituted decision-maker at the first available opportunity. I understand that it is part of the practice that is undertaken in Western Australia.

But what happens if the so-called medical research is invasive? Then what? Where is the line? Where is the line as to what is considered to be, shall I say, "a little bit invasive" and "very invasive"? Where would the line be for members? If you are unconscious and your next of kin or substituted decision-maker has not been contacted, it is not conventional medical treatment that is being provided to you, it is something unconventional, it is some form of medical research—

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where is the line? I imagine that if we ask the 36 members of this chamber, we might probably get 36 different lines, and that is okay because at the end of the day the medical research is being performed on that member or that person.

If I have a continuing concern about the regime as a whole, my concern is that there will be no express parliamentary oversight once this bill passes, and it is not clear to me that there will be express executive oversight on this. A statutory review process was created when we last had this debate in 2020. I see nothing of that sort in the bill presently before us and I wonder why. It is not because there were necessarily any significant issues identified in the statutory review that was eventually tabled, but as I say this is an evolving area; we are talking about medical research. In the last two or three years while this legislation has been in place, invasive types of medical research may not have been being performed on Western Australians without their consent. That may well be the case. What is to say that that will not be the case tomorrow or next year? Who will be watching over this? Which committee of the Parliament will take responsibility for expressly looking at this matter? Are we just going to now pass this bill and just say, "She'll be right, mate. Don't worry about it." I am uncomfortable with that type of non-existent oversight. If there is any concern, it is not a concern with the clauses within the bill, but the bill before us could be enhanced by the creation of some overt oversight mechanism. When I say overt oversight mechanism, I am not talking about the Department of Health and the Department of Justice having some kind of general oversight of all these things and from time to time they do reviews and so on. Members will know that that is not what we are talking about. Last but not least, as the clock is running down, my final concern is about the title of the bill that is before us. As members will see, the long title of the bill is -

An Act to amend the Guardianship and Administration Act 1990 ...

This is not the bill that the Attorney General promised six years ago would be expedited. Members will be aware, because if I have said it once I have said it a thousand times, that the Attorney General promised there would be an expedited bill on the Guardianship and Administration Act 1990, not on the matters that are contained in this bill, but rather on elder abuse reforms. "Expedited" is not my word; it is the Attorney General's word. A Select Committee on Elder Abuse was set up in the last Parliament. The hardworking parliamentary secretary representing the Attorney General was on that committee.

Hon Matthew Swinbourn: Not in that capacity, though.

Hon NICK GOIRAN: The parliamentary secretary was on that committee in a private capacity. It was a four-person committee. Nothing has happened on this matter. It is now six years later, and although the McGowan government will be very quick when it comes to World Elder Abuse Awareness Day to say how much it supports the fight against elder abuse, the record will continue to reflect that there has been no sign of that bill, and there has been no explanation or apology from the Attorney General whatsoever. I wonder whether the parliamentary secretary will be able to update us on that as well.

HON DR SALLY TALBOT (South West) [3.46 pm]: It is always a good way to end the week by sparring with Hon Nick Goiran across the chamber. At this stage on a Thursday afternoon we find those reserves of energy that earlier in the week we wondered whether we had. However, I am not going to spar with Hon Nick Goiran. I want to reflect on some of the aspects of his contribution to the debate as well as some of the things that were said by Hon Tjorn Sibma, who I understand is the shadow minister. I also want to point out a couple of places where I think there is indeed cause for further reflection on how we do these things. I find myself disagreeing with both the contributions from the other side of the chamber about the nature of some of these problems, and I want to spend a bit of time this afternoon teasing some of that out.

I will start by going backwards and commenting on the interesting observation made by Hon Nick Goiran that if we took an ethical problem, such as those presented to the human research ethics committees in relation to medical research, particularly about people from whom consent cannot be obtained, and asked the 36 members of this chamber what their view would be, we would probably end up with 36 different answers. That might be true. However, I say to the member, with my background in philosophical ethics, that he might end up with 36 different answers but I suspect that he would find only one or two different frameworks according to which people make those decisions. Those frameworks are the things that interest ethicists. They are the principles that we bring to our resolution of these problems. Many of these problems are wicked in the sense that it is not just that they do not have obvious answers but that they actually may not have answers. In that case, we may be forced to proceed without the clarity that we would normally be seeking, because the circumstances themselves do not generate that type of clarity. Therefore, I thought it would be interesting to pick up the end of the speech from Hon Nick Goiran and use that to start mine.

One of the things that the Standing Committee on Legislation—of which I was the chair, as the honourable member noted—was able to do was draw on the expertise of people who have been involved in this professional area of work for many years and between them must have thousands of years of experience. I am also tempted to say, and it is not beneath me to have a swipe across the chamber, that it also tells me there is a very good reason to listen to medical rather than legal expertise in these situations, and that is a principle I know is debated on a regular basis by jurists, philosophers and people who think about the practice of medicine. Who are the people best placed to

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make these decisions? Sometimes I think one has to say that it is the medical practitioners, not the legal practitioners. Several times during the course of this inquiry something was brought home to me very strongly; that is, we were hearing something that in some important sense, which I hope to tease out over the next little while available to me, it was important to go beyond that commonsense approach that a legislator might bring and listen to what medical advice was from people who had been dealing with these situations on the ground on a day-by-day basis.

So much connected with this bill that has been brought into this chamber by the Parliamentary Secretary to the Attorney General is unusual. Let me start with the inquiry by the Standing Committee on Legislation. I have been on the Standing Committee on Legislation since 2005, and I think I am right in saying that this is the very first time that the committee has considered an act rather than a bill. The legislation committee is not usually used as a reviewer of legislation; it is used as reviewer of proposed legislation. It might be called into action at different points in the parliamentary procedure, and those members who have been around for a few years will remember that in this regard I often make reference to Hon Giz Watson, who passionately believed as a matter of principle that almost all legislation should be referred to a scrutiny-of-legislation committee before it ever hits this place, on the basis that it would mean that by the time it came into this chamber and was second read, it had already been scrutinised by a committee with the express remit of doing that job. That is not a bad argument. It is one that we could have; it is one that we have periodically returned to in this place and undoubtedly we will again. In this case, the bill went through the chamber under the emergency provisions invoked because of the COVID epidemic at the beginning of the pandemic, and one of the agreements during the passing of the bill was that it would be sent straight to the Standing Committee on Legislation. We then had a very particular remit. It was an interesting process and one that should perhaps be considered. When we talk about review clauses in bills that we look at, we do not often think of writing the legislation committee into a bill in that way, and perhaps we could start doing that—I do not know. I just throw that out there for consideration.

In this rather unusual chain of events, we dealt in this place with the bill in April 2020, and it was referred to the legislation committee right at the beginning of April. That was when it went through this place. The committee was to report by November, so we were given something like a seven-month reporting period. We did indeed report in November; we reported on time. That made the whole process of little bit unusual, but it also meant that the evidence we drew on was exceptionally well considered. I want to underscore that point with some emphasis. I do not mean to imply that the standard of evidence that scrutiny-of-legislation committees are provided with is generally of a lower standard; that is not quite what I mean, although I know it comes out sounding a bit like that. I mean that we heard from a range of experts in the field who had had a long time to consider what was happening and were able to give us their very well thought through reflections on what we ought to be doing to improve the situation in Western Australia. It was not at all dry. It was one of the most interesting inquiries I have ever been involved in and I think, perhaps, Hon Nick Goiran would agree with me.

Hon Nick Goiran: Yes, I agree.

Hon Dr SALLY TALBOT: That is because it involved a number of ongoing research projects that had been effectively grounded in some circumstances that, as the chair of that committee, I have to say that I am not 100 per cent confident we got to the bottom of.

Hon Nick Goiran: I also think that is a fair observation.

Hon Dr SALLY TALBOT: It was quite unusual, and that is putting it very mildly.

Hon Nick Goiran: In fairness to us, honourable member, we were dealing with it hot on the heels of the debate, so we did not have the benefit of all the data that the statutory review people have.

Hon Dr SALLY TALBOT: That is true, and the two opposition speakers, Hon Nick Goiran and the shadow spokesperson, also pointed out that there is more distance to go on this. We have not yet actually reached the end of the process of sorting out how we conduct medical research in this state. We have a long way to go and lots of interesting material to consider in that debate.

When I heard the second reading speech made by Hon Matthew Swinbourn, the parliamentary secretary representing the Attorney General, I was reminded of the rather extraordinary precursor to the bill's coming into this place. It was a statement he made at the end of the first paragraph of his second reading speech, and I have it here highlighted in yellow. I dug it out this afternoon. I will give a little bit of a preamble; the sentence before was —

The amendments to the GAA were an important reform during the early days of the coronavirus pandemic.

I should be more specific. This is a speech made by Hon Matthew Swinbourn on 22 February this year, about three weeks ago. He was talking about the changes we made to the Guardianship and Administration Act in 2020 —

The amendments to the GAA were an important reform during the early days of the coronavirus pandemic.

And then he says —

This was due to the GAA not permitting represented persons to be enrolled in medical research at that time, either with the consent of their decision-maker or in urgent circumstances.

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If someone is coming cold to this debate, it would be reasonable for them to assume that what we had to do in 2020 was in the light of the extraordinary circumstances that we were presented with, in the form of a global pandemic. It was a global pandemic that was represented by a disease that people simply did not understand. I know it was a SARS virus and SARS viruses had been well researched, but that particular manifestation, with its zoonotic parameters, made it into something else. We could not predict where it was going. I do not need to highlight those times of incredible uncertainty about whether we were all going to die.

The proposition was that in order to get the very best medicine for everybody, we might on occasion need to do research on people who did not have the capacity to give their permission to have that research done. It is fairly clear why we had to do this in 2020.

The other day, I heard a story that made me think very much of what the mindset was in 2020, when we simply did not know what was coming. I was talking to a friend of mine who spent 2020 nursing in emergency medicine in America. She is an intensivist, and she was nursing in intensive care wards in America in 2020. She had tears in her eyes when she told me this, three years later. She said that they saw things there that they never thought they would see on wards. I am sure the people in this chamber with medical experience, which I do not have, such as Hon Dr Brian Walker, can imagine what she was talking about. She said to me that they did not really know what would happen to people if they spent weeks immobile. We all know that when patients cannot move themselves, there is a protocol—it has a name—to move patients regularly so that they do not get pressure sores. It is called the something protocol. Hon Dr Brian Walker is not going to help me because he cannot remember what it is called either. The nurse said that they had no idea what would happen to people. They knew about bedsores, but they did not really know what would happen to people if the medical practitioners literally could not do that, and they could not do that for some patients for three or four weeks. She said that the results were absolutely horrendous. I think we were right to panic. When she told me that story only the other day, I felt a chill go through me and thought, "We are not over this yet."

When we started this inquiry as part of the Standing Committee on Legislation process, we discovered that a change had happened in Western Australia a couple of years before 2020. Until that time, we had been doing research on people who were not able to give consent. Being good, diligent researchers into these matters, we went looking for what had actually happened. I turn now to the report to give members a flavour of this. It turned out that the problem had originated—I am not exactly sure when it originated, but sometime between 2013 and 2017—when a conversation started between the Department of Health and the State Solicitor's Office, undoubtedly involving all the Department of Health lawyers and a number of different individuals who had been co-opted into this discussion, about whether the assumptions we were making about the legal safeguards protecting medical practitioners who were undertaking research when people could not give consent were correct. The assumption that was being made was that if someone had given consent to medical treatment, it could also be assumed to facilitate consent to medical research. That was the assumption that had been made for a long time up until somewhere around 2017. That is, when somebody had properly obtained consent for medical treatment, that also implied consent to be involved in medical research.

I want to pay a particular tribute, with the greatest respect, to a man whose evidence I found extremely helpful and who has subsequently become—I think I can be bold enough to say—a friend. He has given me some very valuable advice in other areas of my work since then. That is Hon Eric Heenan, QC, who was one of the committee's first witnesses and who has been absolutely assiduous over the last few years. I see Hon Nick Goiran smiling because I know that, like me, every time he sees Hon Eric Heenan coming down the corridor towards him, he knows that Hon Eric Heenan is going to say, "When are you going to fix that sunset clause?" I am glad to say that we are doing it now, Eric! That is in large part to do with the assistance that he provided to the committee by way of his evidence and his submission at that time.

I want to start by giving members a flavour of how this peculiar situation came about. I am going to quote directly from the evidence given by Hon Eric Heenan, QC. He said —

For many years before the —

Health department of Western Australia —

directives of 2018 medical researchers, institutes, hospitals and other doctors had worked on the assumption that patients who were temporarily or permanently incapacitated from giving personal informed consent to participation in a clinical trial or other medical research could be enrolled in such a trial or research if a close relative, spouse, guardian or trusted friend responsible for the patient's care was prepared to make an informed decision to consent on the patient's behalf to participate in the trial or research. This was done much in the same way as doctors and hospitals accepted the consent of such a person on a patient's behalf to undergo surgery or other forms of treatment, especially urgent treatment, when the patient was unconscious or unable to consent himself or herself. There are obvious comparisons here with the well

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accepted practice of parental consent on behalf of children too young to consent to participate in surgical, medical or dental treatment.

The committee's interest was obviously more than piqued by that submission. When Hon Eric Heenan appeared before the committee as a witness, we asked him to expand on that aspect of his submission. This is what he said at the hearing held on 30 September 2020 —

This is a difficult matter. The question assumes that this practice was not legal until the introduction of the amendment —

He is talking about the 2020 amendment to the Guardianship and Administration Act —

and that is something which I think is probably controversial. There was certainly the opinion from the State Solicitor's Office to the health department, which I have never seen and as far as I am aware has not been published, which advanced the opinion that research of this kind was not permitted, but I know there are shades of opinion about whether that is entirely correct. My own view is that in certain kinds of research, it probably is correct, but there are other kinds of research—what doctors call the comparative analysis between existing orthodox treatments—and I would not have expected that to be in contravention. I think the situation really is that up until 2018, the medical profession and the universities genuinely believed that it was permissible to have research for people who could not consent, so long as consent was forthcoming from some responsible adult carer or guardian or parent, in the same way that treatment could be given.

But, as I have said in the paper, in 2008, the Guardianship and Administration Act was amended to identify people who could consent to ordinary treatment—not research; ordinary treatment—for disabled persons or persons who were unable to consent, and there is a hierarchy of people that we all know about. My own view is that by defining those people who could consent for this form of treatment, there was an unintentional implication that they could not consent to anything else. If you couple that with the idea that research is distinctly different from treatment, you see that the consent powers are confined to treatment, and not this different activity of research. Although I have not seen the opinion, I have heard others express that view, and it seems to me to be quite a logical inference to draw. I think it is a flawed inference. I think certain types of research could not be classified as treatment, but other forms of research certainly could, and for those that could be classified as treatment, I do not see that there was any departure from the existing law or proper practice in the procedures that had been followed.

He speaks as clearly as he writes. It is very obvious what he is saying. He speaks directly of this matter with his background of having been on a human research ethics committee for many years. He has been absolutely at the core of this issue right from the beginning.

What happened in 2018? For members who are interested and want to do a little bit more follow-up, because I suspect that this is not by any means the last time we are going to see the GAA come up for debate in this place, maybe not in this term of government, the committee tabled the guidance from the Department of Health dated December 2018 as appendix 4 of its report. This is the only public document that explicitly goes into the detail and specifies what the change in 2018 was. It is a two-page document. I do not have time to read it out now, but if members are interested, it is there as appendix 4 in the committee's report.

I will talk now about the experience of practitioners in 2018, once the Department of Health had taken whatever it was it got from the State Solicitor's Office and turned it into practical advice for practitioners. It sent out a directive in 2018 that basically said, "You cannot do what you've been doing."

The committee received a raft of evidence in this regard. I will refer to just two or three elements of it to indicate that this was not people who did not know what they were talking about. These were people with vast experience. The committee asked stakeholders—we were still establishing the background—whether they were aware of any negative consequences of doing what they had been doing before the 2018 advice from the Department of Health and before the preceding advice from State Sol's. Had something gone wrong? Had there been some kind of event—a whistleblower or someone who was not feeling quite comfortable with what had gone on?

The committee asked whether stakeholders were aware of any negative consequences that arose from conducting medical research on incapacitated people prior to 2018. Clinical Associate Professor David Mountain from the Australian Medical Association responded —

No. That was one of the strangest things about it. There are lots and lots of trials and lots of human beings, so there are errors and audits that would have said, "You can do this better", but, no, we had no serious adverse outcomes or no trials that had been stopped with major harms to patients because of a poor trial process. In fact, we follow very similar practices to the rest of Australia, it is just that our legislation happened to be silent. The interpretation was about whether silence meant that it was precluded or silence

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meant that you could follow what was the best practice at the time. Certainly, we had no evidence that there was any significant, serious malpractice going on within Western Australia. In fact, we would probably be seen as one of the legislatures with very good levels of practice, particularly in critical care, because we had a high number of international-level researchers in these areas.

That is pretty clear. We then went to the staff specialist in emergency medicine at Royal Perth Hospital, Dr Stephen Macdonald, who said, in response to the same question —

I am not aware [of any adverse consequences]. I am happy to be put right on that. My understanding was that the provisions within the guardianship act were interpreted, obviously, for proxy decision-making by a substitute decision-maker for treatment, and that the approval by ethics committees was based upon the principles set out in the National Statement. In other words, for that to apply, all the criteria that are set out in the National Statement were used in the ethics decision-making process, and that from a research-governance point of view, the research could happen, particularly involving emergency care in scenarios such as I have explained where there might be observational research where there is low-risk negligible research, as defined by the NHMRC ... statement, was permissible.

The report contains a raft of those comments. I will leave it to interested members to look them up for themselves if they want to take it further. It is interesting that both witnesses refer to work that is done in emergency situations. When we are talking about medical treatment or medical research that is carried out on people who are not able to give consent, we might think of people who are not able to give consent to anything in their lives at that time, perhaps because they have dementia or some sort of neurological damage and they have had a permanent decision-maker appointed for them. But of course the other category of people we are talking about are people who have suddenly been taken out for an adverse medical event and need emergency intervention with the object of saving their lives. Those people cannot give consent to medical treatment. I make that point very strongly because this was one of the pieces of research that was stopped in its tracks by what happened in 2018. That was the same research trial to which Western Australia was a major contributor. I know that it was carried out nationally, across Australia, but I am not sure whether it was carried out internationally. My understanding is that that research stopped in 2018 when Western Australia pulled out. It was looking at the level of oxygen given to people in ambulances when they have had a cardiac arrest. It specifically looked at what happened to those who suffered a cardiac arrest outside of hospital. The provisions are different for those who have an arrest in hospital. When someone goes into cardiac arrest, 000 is dialled, the paramedics arrive, and the person is put on oxygen. In the committee hearings it was pointed out to us that some of the effects of oxygen dosage are well known. The example given to us was that if a baby is given 100 per cent oxygen, they go blind. We know now to never give babies 100 per cent oxygen. What mix of oxygen do we give a person who has had a cardiac arrest and is with paramedics or in the ambulance before they get to hospital to increase their chances of survival? My recollection is that the research had been conducted using limited variations in the mix of oxygen. It was not as though some people were not being given oxygen at all or whether they survived as well as people who were given oxygen. The mix was changed from a percentage—I am making this up now. If members really want to know the figures, they will have to check the research. The variation of oxygen in the mixture was minuscule and something like 55 to 58 per cent.

That research had been going on for some years but Western Australia had to close it down because the paramedics could no longer vary the oxygen dosage. They had to give patients the dosage prescribed in the current medical regulations, and so that research collapsed. That is a pretty serious thing. It seems to me that that would be one of those things classified as an unintended consequence when whomever it was—I stress that it did not happen in 2020, because in 2020 we enacted legislation that meant that that research could restart. It did not actually restart for reasons that I will come to in a minute if I have time, but whatever had happened before then had stopped that research because people could no longer participate if they were not able to give consent. Hon Matthew Swinbourn has a puzzled frown on this face.

Hon Matthew Swinbourn: No, I am just marvelling at your contribution.

Hon Dr SALLY TALBOT: He is engaged. He is not worried; he is happy. That is his happy face.

Hon Matthew Swinbourn: It's the only one I have.

Hon Dr SALLY TALBOT: It is the only one he has got. I have distracted myself by looking at Hon Matthew Swinbourn. Look the other way.

What I am getting to is that in 2020 we were trying to fix the problem that had started for whatever reason. Members can write the story because I cannot put my hand on my heart and tell them that I am clear about how it happened, but everything closed down in 2018.

In 2020, the Guardianship and Administration Amendment (Medical Research) Bill 2020 was put forward under the COVID umbrella, and quite rightly in my view because that was the impetus to fix this problem as quickly as we could. The referral of this bill to the Standing Committee on Legislation was absolutely the right thing to do, and

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discussing the Guardianship and Administration Amendment (Medical Research) Bill 2023 today and removing the sunset clause is the right thing to do. We know that it is unlike my colleague Hon Nick Goiran on the other side of the house to not want to take full credit for something, but I notice that he is crediting Hon Michael Mischin and Hon Aaron Stonehouse for coming up with the idea of a sunset clause. I think we all agree that it is a very good thing to remove it. The trouble with putting the sunset clause in the bill was that we did not really enable that kind of research to start again. Medical research is a bit like an enormous ocean liner. It cannot suddenly turn left or stop. It has to be given something like 27 kilometres to come to a halt. It has to be powered up for hours and hours before it can move out of port. When the committee reported in October 2020, we found that even the paperwork for restarting research with the people who did not have capacity had not been done, let alone the research submissions and the ethics committee considerations. Even the forms had not been designed! They had by the time we reported. I would like to claim that as something that the scrutiny of legislation committees can do. When committees express a certain amount of surprise that a piece of legislation has been in place for five or six months and there is no paperwork to support it with the main stakeholders, all of a sudden, they find draft forms in front of them. It all happens very quickly. I take my hat off to ministers' offices that ask their staff to listen to the live broadcasts of committee hearings. We did actually get that done. I think that was a good thing.

My point is that it needs a lot more than just the forms that the researchers can fill in. It is a very lengthy process, and quite rightly, too. There is a sense in which this kind of research is never an emergency response. I am using "emergency" in a different context than might be used in terms of responding to medical emergencies. Ethics committees have to give due consideration to every element of a research proposal. That is not something that is done quickly.

That hiatus in research in Western Australia, and we have witnesses who can confirm this for us, is going to take years to wash out of the system. It is such a sad thing. We hear so often in debates in this place that Western Australia is at the cutting edge of so much research and technology. We have done development not just to medical industries but in industries across the board—green technology and all that sort of thing. We were right at the cutting edge. Suddenly in 2018, a lot of this medically based research stopped. I think it is very sad thing that that happened. It grieves me that it is going to take years to get ourselves back.

Having said that, having seen the energy, passion, commitment and dedication that the professionals brought to our hearings and are still contributing to the process, I have no doubt that they will do everything that can humanly be done to get things up and running again. I do think it is a bit of a stain on Western Australia's reputation. That saddens me, because I am not sure that it was necessary. I take all the points made by Hon Nick Goiran about the need to be circumspect and cautious about these things, but I hope that, in the future, if I a similar situation arises, we will be more agile, creative and constructive about the way that we respond to these things.

Where did we get to after all that? I wanted to share with members some specific things about the research projects that stopped, but I think I am rapidly going to run out of time if I do that. I might leave that, perhaps, to another day. I want to come back to this basic point. I suspect that this is something that we might draw on to guide us in future if ever we come up against a comparable apparent impasse when we have what might be called a false dichotomy created between treatment and research. Again, I am going to just refer members to chapter five of the committee's report, page 44, and particularly to a document that was tabled by Hon Eric Heenan, QC. In that document, he goes into some detail about the need to be very clear about what exactly is meant by treatment and research. I draw members' attention specifically to paragraph 5.4, which reads —

The Committee heard from a number of medical professionals who criticised the ban on involving incapacitated research candidates in medical research which existed between 2018 and October 2020. They gave real world examples of medical research involving comparative studies of accepted medical treatments to illustrate the importance of allowing medical research to resume under the Guardianship and Administration Act 1990. These included ...

Professor Gary Geelhoed spoke about his experiences; Dr Stephen Macdonald is the doctor who talked specifically about that exact trial. Members will find those details on page 46 of the committee report. This is just to show that I am not making any of this up, as it is all well documented, as slightly shocking as it seems.

I have six minutes remaining. The two specific changes in this act are very much welcomed. I have talked enough about the revoking of the sunset clause. There is no question that that is the right thing to do. Again, I hope that we will be able to see a speedy start-up of many of these projects.

The second matter of the lead researcher is interesting. I suspect that what was missed in the original drafting of the 2020 bill was the extent to which research inevitably involves a research team.

I always remember at school when I was quite young, probably about six or seven years old, the teachers played a trick on us. I always remember this because I feel bad about it to this day. All the children were asked to draw

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a picture of a scientist. We all drew a picture of a scientist, and every single one of the 30 children drew a picture of a bloke in a white coat. The whole point of the lesson was that girls could be scientists.

Hon Nick Goiran: And glasses?

Hon Dr SALLY TALBOT: Yes—and glasses, and test tubes boiling over, and all that sort of thing, but they were all definitely blokes. They all had moustaches and beards and things like that. I think that sometimes when we talk about —

Hon Matthew Swinbourn: They are sitting over there!

Hon Dr SALLY TALBOT: There are people with beards and moustaches sitting over there.

Hon Nick Goiran: This is dangerous territory, honourable member! I'm surprised you're going there!

Hon Dr SALLY TALBOT: No, but members see my point: in those days, ever so many years ago, everybody assumed that scientists were blokes. I suspect that when drafters think about scientists, they tend to think that we have the lead scientists at the top, and then underneath are all the subjects of the research. Of course, it simply does not work like that. Without teams, we could not run medical research.

Hon Matthew Swinbourn: There are very many well-qualified female scientists.

Hon Dr SALLY TALBOT: Absolutely, Hon Matthew Swinbourn, and many of the members of those teams, including lead scientists, will of course be women, as they would have been in those days. It was just a way of pointing out how prejudiced we all were by our conditioning. Recognising that every research project is run effectively on a day-to-day basis by a team, it makes absolute sense to broaden this definition of "lead researcher".

Members will notice that the committee also recommended that some changes be made to the idea of an independent medical practitioner. The government has not agreed to do that. Having been through the report from the Department of Justice, I now see that the department has in fact provided the clarity that the committee found lacking in the definition of "independent medical practitioner". That is specifically referred to in paragraph 7 in the executive summary in the report by the Department of Justice. It refers to the works being done by the research governance service in the Department of Health. I think that is a very positive thing to have come out of this.

There is a lot more that I could say about this bill, but I have two and a half minutes left, and I think that the President is going to note the time and stop me.

The PRESIDENT: Right now.

Hon Dr SALLY TALBOT: I will finish my remarks there.

Debate interrupted, pursuant to standing orders.

[Continued on page 1071.]