COMMITTEES Community Affairs Committee Report

Senator MILNE (Tasmania) (10.05 a.m.)—I could not disagree more with Senator Humphries. Frankly, I find it offensive that he should stand here and say it is a storm in a test tube. We are talking about the treatment of cancer patients around Australia and their ability to access a technology which gives more accurate diagnosis and is a more focused diagnostic tool than anything that was available at that time or since. As Senator Moore, the chair of the committee has said, we have had evidence and have concluded as a committee that over the years PET technology has come into its own more and more. In fact, it has been demonstrated not only to be safe and clinically effective but also to be cost effective because it avoids unnecessary and costly treatments and, in many cases, operations.

I went to the Peter MacCallum clinic with Senator Moore and Senator Polley, and we saw for ourselves exactly how good this is as a diagnostic tool. In part, our Senate committee inquiry was to look at whether the Department of Health and Ageing had obfuscated or misled the Senate committee and the Senate over time in relation to information on this. The inquiry was also to look at the significance of what occurred. I think it has been highly significant. The impact of the changed supporting committee report—and I will come to that—has been that this technology has not been rolled out around Australia as fast as it would otherwise have been. That means the long delay in getting the best information to vulnerable cancer patients has, in my view, been likely to have diminished their ability to help themselves and has caused a great deal of needless suffering, irrespective of the Medicare funding decision. That sort of outcome is the opposite of what was promised with MSAC.

Let me go back to how it happened. The former Minister for Health and Family Services, Dr Michael Wooldridge, had been involved in a massive scandal in the late 1990s—a scandal known as 'scan scam'. It was around the magnetic imaging machines. At the time they were being rolled out there was a massive scandal as a result of a budget leak and as a result of alleged links between Dr Wooldridge, people in the industry and so on. So when, shortly after the scan scam, an approach was made to the government of the day to assess the PET technology, what the minister of the day did was to add into the MSAC a special committee. They had set up a process by then to assess new technologies so that the minister would not be involved in apparent scandals like that in the future and to try to set up an arms-length process. What happened with this one, though, was that there was a special committee added in, which had not happened before. It was a unique event in the history of MSAC assessment. It was a steering committee, and this process was established at the request of the minister because of concerns over the potential expense of PET to the Commonwealth.

So this committee was added in with the significant purpose of looking at the cost to the Commonwealth, because the implications were that, if this had been found to have been safe and clinically effective, it would have had to have been rolled out and a Medicare rebate would have had to have been provided. These scans cost somewhere between \$800 and \$1,000 per scan, so you can imagine the cost to the Commonwealth if a finding had come out saying that they warranted unlimited Medicare funding. That would have been a massive hit on the health budget at the time, especially because at that time there was agreement—and everyone agreed—that it was only potentially cost-effective. It

certainly would be helpful to cancer patients, but would it be cost-effective? We now know that it is more than cost-effective because it saves money, as it saves unnecessary treatments and things, but at the time that was not as clear as it has become since.

So this special steering committee was inserted. It was ministerially appointed. Its chair, Professor Kearney, in October 1999, at the first meeting of the steering committee, noted:

... should the technical evaluation of PET prove inconclusive, some sort of data collection regime would be a reasonable condition for wider introduction of PET.

So he was already saying that the technical evaluation might prove inconclusive. Then, at the second meeting of the steering committee in January 2001, he was minuted as saying:

The committee should prepare itself for the possibility that the MSAC supporting committee report would find that the evidence for PET is not sufficient to warrant widespread dissemination of the technology, in which case it is likely that the status quo would be retained or a very minimal rollout may be recommended.

He was already saying that before the expert doctors committee, the supporting committee, had even met. So here was the chair of the ministerially appointed steering committee to oversee how much money, effectively, the Commonwealth would wear already warning what the likely result would be, before the experts could meet. Then the supporting committee met and it found that PET was safe, clinically effective and potentially cost-effective.

That is what the experts found. However, their report was changed and not only was the word 'potentially' inserted before 'clinically effective'—therefore implying that it was unproven, which was certainly not found—but an additional primary finding, which Senator Humphries chose not to mention, was inserted at the front of the report, which took away the statement in connection to whether it warranted unlimited funding. That was removed and a straight-up statement was inserted to say: 'There is insufficient evidence at this time from which to draw definitive conclusions about the clinical effectiveness and cost-effectiveness of PET.'

That is completely wrong. That is not what the supporting committee found. That was inserted in there and the expert doctors, who had found something different, were never told that their report had been changed. The only people who knew it had been changed throughout the whole process were Professor Kearney and Professor King. They were on every single committee. They were on the steering committee, ministerially appointed, they were on the expert doctors committee and they were on the MSAC itself and on the MSAC executive. So they knew through the process, but they never, ever told MSAC, when it made its decision about what to recommend on how much funding should go out there, that the experts had found something different.

As a result, those experts on that supporting committee for the past eight years have had to put up with the fact that they are out there advocating for this technology and people have been throwing in their face, 'Well, if you really think it's so good, why did you find all those years ago that it was only potentially clinically effective?' That is why they have fought so hard over these years to get the record put straight, to say that that is not what they found. They did find that it was clinically effective. We have at least fixed that up. I am really pleased that the committee has recognised that the expert doctors report was changed, that it did matter, that it has compromised the reputation of people such as Professor Hicks and others who have advocated for it, such as Dr Ware. I am really pleased to endorse the apology to them because not only has Professor Hicks suffered because his name was on the report but also Dr Ware was insulted throughout by the health department, which in the end had instructed people not to continue with correspondence with him, not to provide FOI and to absolutely obfuscate and frustrate any attempts to get to the truth.

So does it matter? Does it matter that a finding came out in 2000 that justified the Commonwealth not rolling out the funding? Yes, it does, because what happened was, even though the doctors said it was safe and clinically effective, the result was that the Commonwealth funding was restricted and a few centres around Australia were designated as data collection centres. If you got the PET scan done at those centres, you got a Medicare rebate but, if you had the PET scan done in any other place in Australia that was not one of those contracted centres, you did not get a Medicare rebate—except for three indications of cancer, whereas the main data collection centres were collecting for 22. The result was that this technology was not made available to cancer patients around Australia and those expert centres were collecting data for something they already knew was effective.

I think there was a deliberate change to this report. I do not believe it was editorial, and I do believe that there is a case to answer from the people who changed it and who failed to tell people that it had been changed. If Senator Humphries wants to stand up and say that is not the case, I am happy to stand up to say quite the contrary. I think there was a political agenda to change the report with respect to funding, at the expense of cancer patients.