



LEGISLATIVE ASSEMBLY FOR THE AUSTRALIAN CAPITAL TERRITORY

STANDING COMMITTEE ON PUBLIC ACCOUNTS

(Reference: Auditor-General's Report No 8 of 2004)

Members:

MR R MULCAHY (The Chair)
DR D FOSKEY (The Deputy Chair)
MS K MACDONALD

TRANSCRIPT OF EVIDENCE

CANBERRA

WEDNESDAY, 7 DECEMBER 2005

Secretary to the committee:
Ms A Cullen (Ph: 6205 0136)

By authority of the Legislative Assembly for the Australian Capital Territory

Submissions, answers to questions on notice and other documents relevant to this inquiry which have been authorised for publication by the committee may be obtained from the committee office of the Legislative Assembly (Ph: 6205 0127).

The committee met at 2.07 pm.

RUSSELL McGOWAN

was called.

THE CHAIR: We will commence this public hearing. I need to read some information pertinent to these proceedings. You should understand that these hearings are legal proceedings of the Legislative Assembly, protected by parliamentary privilege. That gives you certain protections but also certain responsibilities. It means that you are protected from certain legal actions such as being sued for defamation for what you say at this public hearing. It also means that you have a responsibility to tell the committee the truth. Giving false or misleading evidence will be treated by the Assembly as a serious matter. The matter before the committee today is the inquiry into Auditor-General's report No 8 of 2004, waiting lists for elective surgery and medical treatment.

Mr McGowan, you are the president of the Healthcare Consumers Association of the ACT, I understand?

Mr McGowan: That is correct.

THE CHAIR: Would you like to make an opening statement to the committee before I invite questions from committee members?

Mr McGowan: Yes. I have got about 10 or 12 minutes of an opening statement to make. Then I would be happy to answer questions. I point out that there were other members of our association involved with these processes, but unfortunately, due to family emergencies, they haven't been able to attend. My apologies.

Waiting times for hospital care have become a political issue. Waiting times are affected by many factors, including the supply of health care practitioners, referral patterns and the availability of operating room time or other resources. We recognise that, whilst the health care system is beginning to show the strain created by factors like an ageing population, capital-intensive medical technology, innovative treatment in care practices and the tighter financial constraints by government—and patient wait times are merely one initial indicator of this pressure—some of the waiting times experienced by patients in the ACT seem to be well beyond the national benchmarks. And the management of them needs improvement.

Research teams commissioned by Health Canada to study this issue in 1998 concluded that, with rare exceptions, waiting lists in Canada, as in most other countries, are non-standardised, capriciously organised, poorly monitored and, according to most informed observers, in grave need of retooling. Where waiting list data are carefully and accurately compiled and routinely monitored, the public clearly benefits.

We would like to highlight in this submission three of the findings of the performance audit: the inaccuracy of waiting list data, the inequities in the current processes for prioritising patients and the need to improve communication with consumers about their status on the waiting lists. We would also like to stress the need to take social factors into

account when deferring access for those not ready for care when offered it.

In our original submission to the audit, we noted that waiting times are one of the most common complaints consumers have about elective surgery and invasive medical procedures. We also know that people are less likely to complain when they are given explanations and communication about what to expect or, in this case, what not to expect. A person may already be in pain and discomfort, and the lack of certainty about the wait time will add to their concern about their health.

In saying this, we acknowledge the recent attempts by ACT Health to improve its performance and accept that most of its responses to the audit findings are reasonable. However, we feel that the current system still does not deal well enough with how a person on the list is treated, whether or not they are kept informed about their place on the waiting list and whether they have adequate health care while they wait or are given other options to try. These are key issues for consumers.

The following observations, derived from HCCA consultations with consumers, may be helpful in drawing this out: firstly, communication about process times and delays is important to consumers and can mitigate perceptions of staff inefficiency or insensitivity. Secondly, satisfaction is linked to consumers' perceptions of the appropriateness of time spent waiting. If consumers are not informed of the reasons for their wait, they and their family members might fear that they have been forgotten or that their medical problem is not being taken seriously. Finally, time spent waiting may be perceived as appropriate if there is an explanation by nurses and staff about the wait. Informing patients of the expected length of the wait can also mitigate the negative influence of waiting time.

We have concerns that the process for setting and revising patient priority is mostly clinician driven. For example, the consumer experience of waiting for hip replacement, which has resulted in limited mobility and pain, could be far greater than another procedure like cataract surgery which is deemed more urgent but is easier to program.

Just as health care is a complex process for administrators, managers and clinicians, it is also a complex process from the consumer perspective. As consumers, we need to coordinate different aspects of our lives in order to access the health services on the date we are given. This means not only changing commitments such as work, family and community activities but also our responsibility as carers—to our children, friends or ageing relatives.

We need to consider the support we may need on discharge and for the days and weeks to follow. This support may also require others to change their commitments. There is a strong ripple effect. By receiving timely and accurate information about what we can expect, we can better prepare ourselves, our family and our support people.

Service standards need to be in place and closely monitored for the management of waiting lists, that is, the service provider must agree to contact potential patients at agreed time points to advise progression on the list and seek updates on the patients' condition and any personal constraints that may impact on their access to surgery. This should be easier for ACT Health now it has centralised management of its services.

Published information hasn't helped many people until now. ACT Health's recent move

to publish information on the internet, about which surgeon or proceduralist and which hospital has capacity and when, may help consumers to make decisions more easily to wait, go interstate or seek private access, et cetera. Problems will continue to be magnified for those patients confined to the public system, particularly where there are cross-border issues. This needn't be the case in a public health system.

As part of the national health system reforms in the UK, we understand they have managed to introduce a system which allows them to make firm bookings for people to have elective surgery, at a time to suit them, not just at a time which suits the hospitals. This approach may be worth exploring further here.

We understand that in other places, like New Zealand, they have a wait list category that ensures certainty that treatment will take place within the next six months. They also have a care and review category which applies to patients with conditions that are likely to deteriorate in the foreseeable future, who have been assessed as likely to benefit significantly from surgery but cannot be offered certainty of public-funded treatment due to the clinical priority and current financial constraints. These patients have an individualised care plan, predominantly private primary care, including a program or process for regularly reviewing their priority for surgery.

Another point of view with some currency is that anyone on a list with an expected wait time of more than 12 months shouldn't be on the list at all; rather they should be monitored and placed on the list when their properly assessed need warrants it. We have sympathy with this approach, especially if it helps to de-politicise the publication of waiting lists, which are notoriously inaccurate because of duplications and failed maintenance and should just be used as administrative mechanisms, not political footballs.

Since the performance audit report was published, ACT Health has attempted to make its rational, 50-page policy on managing elective surgery waiting lists more comprehensible to the average patient by preparing a two-page consumer version. We don't know whether it is currently in use or whether it has helped staff as well as consumers to understand how the system is supposed to work, but here are some of our comments about it at the time it was proposed earlier this year.

There are some elective surgery procedures which cannot be performed in ACT hospitals. The full policy uses the term "eligible elective surgery". Examples of procedures that are not eligible include some forms of cosmetic surgery. Thus the statement in the draft that "elective surgery patients will have their names added to the elective surgery waiting list" is not completely correct. The consumer version should at least make reference to this.

The full policy has a much more comprehensive description of the term "priority". The consumer version has very little information, other than "clinical need" and "social factors". The consumer version should at least include the comment: "If all other things are equal, the treatments will be on a next-in-line basis." This is different to being given "special consideration", which is what the consumer version says.

Consideration should be given to including a section on removal from the waiting list and the ability for a person to defer their surgery. The consumer version makes no

reference to the fact that people can be removed from the waiting list or why, in particular if contact is lost with the person, for example, because they have moved. It would be useful for people to know that this could happen and that it is important for them to inform the hospital of any change of contact details.

The document should make reference to the ability of people to appeal decisions—for example, the category of clinical urgency or removal from the waiting list and information on complaints processes. The final version should be made available in community languages and in different formats.

I am happy to answer any questions you might have on this submission.

THE CHAIR: Thank you. That was a most interesting presentation. You talked about the UK having the capacity to book. Is that for public patients under the national health system there, do you understand?

Mr McGowan: Yes, it is.

THE CHAIR: What has the impact of that process been? Has that taken a bit of stress out of it? Has it led to reductions in waiting lists or is it more for comfort purposes?

Mr McGowan: It is both. As part of the national health service reforms, they fit quite a lot more resources into the system. They have also changed the way they are doing their business. They are realising that they have to make the system patient-centred. You don't run a system for the convenience of the people working in it; you try to meet the needs of the people that are using the system.

THE CHAIR: If somebody was, for example, still in the workforce and clearly needed certain surgery—say they were in teaching—it would be desirable to have that in summer when there would be less demand. In the UK system they could elect to have the operation in the period that was most suitable to them?

Mr McGowan: That is right, and when they can have the right supports in place to take on their other family and social roles that I referred to in the submission.

THE CHAIR: We didn't seem to hear enough weight given to that when we heard from the minister, but we can go into that later. The other matter relates to the waiting lists. I wasn't quite sure where that would end up, under what you are proposing, if you put on a 12-month cap. I share your concern about it being political. Surely, in certain areas of surgery where there are specialisations where we have insufficient specialists and too much demand—maybe orthopaedics; I can't recall immediately whether that was a long process; you may have people who need a hip replacement operation but the list is so long that they have no prospect under 12 months—how would you see those people being dealt with? They have not a life-threatening condition but certainly one that is causing them a lot of distress. If you have reached the 12-month period for those procedures, how would you see those patients being dealt with under your suggestion?

Mr McGowan: Part of it is that you would be constantly monitoring the impact of the disease on the people. If they were originally assessed as the lowest category so that they wouldn't be able to be programmed in the quickest possible time, they would still have

to be monitored for any deterioration which might impact on that. That is some of the detail that I mentioned about being in a category where they are monitored. In the system that they are using in New Zealand, they monitor these patients.

It is a matter of whether you list them on a wait list, not whether or not they are assessed as potentially needing surgery. I know I potentially need cataract surgery, but I'm not on any wait list for that at the moment, for a number of factors, but I constantly monitor it with my ophthalmologist. We review it every time I see him.

THE CHAIR: Take that case study. If there were so many people who needed that procedure and their specialist said that it ought to be attended to in the near future and that list is greater than the 12-month wait because there were not enough surgeons, how do you tackle that?

Mr McGowan: That becomes a matter of availability of resources, which is an issue for government to take up.

THE CHAIR: Would it not be desirable to at least have those people on the list, in the event that there are cancellations along the way? Are you suggesting that they go away and come back? I am not talking about people who may not have a relatively urgent need. I accept that line of argument. How do you deal with the others?

Mr McGowan: That was merely one perspective I have heard around clinicians circles that a waiting list where the wait time is longer than 12 months is fairly meaningless because it is very hard for people to program their lives around an event that is so far in the future that it can be so uncertain. It becomes meaningful if it is within the next six or 12 months. That is the point of having waiting lists that focus on those things, which isn't to say that there isn't still need in the community beyond the people who are on those waiting lists.

THE CHAIR: You mentioned the possibility of giving people the right to appeal if they were taken off that list. Would you contemplate that being of their own volition or with the support of a medical adviser? I could contemplate a situation where people might feel they want the procedure but the resources aren't there and the clinical view is that it is not really of such priority. Would it not be desirable to have some check there to ensure it was medically based?

Mr McGowan: There should be appropriate sources of information to allow people to make rational decisions about any action they take in this regard. Certainly, some people have greater expectations of the system than the system is ever likely to be able to deliver. Being able to feed that to them is important. Ultimately, people should have a right to appeal, regardless of whether their appeal is irrational. There should be a fair mechanism for hearing that appeal and communicating the result to them. That isn't always the case at the moment.

DR FOSKEY: That was a useful introduction. It doesn't leave a lot of questions to be asked. Is this a burning issue amongst consumers that you are in touch with? How would you rate it amongst people's concerns?

Mr McGowan: I would have to say no, it isn't a major concern for the consumers that

we are in touch with, but there may be other sectors of the community, particularly older people with deteriorating conditions where it may be more of a factor, who are not currently involved with some of our networks. We would like to be more in touch with them. We would then try to raise issues that those people raise with us. No, it isn't something that our members constantly raise with us as a concern.

DR FOSKEY: In a sense, it is one of the main things that the media like to focus on? It doesn't necessarily reflect other concerns that could do with a lot more airing publicly?

Mr McGowan: That is possibly correct. If you only worry about the things that you can measure, and you think you can measure these things, then you will worry about them. We have raised concerns about the way in which these things are measured anyway because we know that some people go on multiple lists and other people have their concerns attended to in some other way, either by going interstate or private, and are not removed from this immediately. All of that maintenance stuff can make the lists a little misleading.

We are supportive of the government's introduction of a broader range of performance indicators in the health system than just elective surgery or procedural waiting times. That being said, some of them still are far too long. We would certainly like to see more resources available to attend to those and more forward planning so that we don't get bottlenecks building up.

DR FOSKEY: Do you think there are some groups that are more disadvantaged than others? You talked about information, education and knowing how to use the process. Would it be helpful if people who are perhaps not in a position to advocate for themselves, for various reasons, had advocates? Do you think that something vaguely like case management would help?

Mr McGowan: Certainly. It is something that we are exploring. You know that, if people go through a process and get an adverse outcome, then they have recourse to a complaints mechanism, but they don't have ways of forestalling those adverse events happening in the first place, such as an unnecessary delay in accessing treatment. It is something which we have recognised.

In other jurisdictions, there are some resources around to help people who are otherwise not able to advocate for better access to health services. We are not resourced to do that ourselves, within our organisation, but we see it as a need and would be happy to work with any other agency that might be able to do that. Often the people who are most at risk are those that only have recourse to the public system and don't have the options of going interstate or privately to get matters attended to. They often can't articulate their need as clearly.

DR FOSKEY: Can doctors be helpful in this situation?

Mr McGowan: Yes. I am sure many of them are, but it is a bit patchy. If you see the doctor on the wrong day and he is up to his—

DR FOSKEY: Eyeballs in work?

Mr McGowan: Yes. Obviously, everyone has their limitations in performance. In general, the public is well served by the clinicians in this community, but that doesn't mean to say that they are organised in such a way that they always provide the best systemic response to client need. It is all based on individual clinician/consumer relationships.

One of the things that are going to change that is this publication of information about who is most accessible. If you realise that going to Calvary with Dr X means you are going to have to wait for nine months, but going to TCH with Dr Y is going to give you access in two months, then you can make a decision based on that.

MS MacDONALD: That leads on to two questions that came to my mind before. I haven't got many questions because it was such a comprehensive introduction on your part. Thank you very much for that. The first question deals with the imminent publication of waiting times for individual clinicians. Has there been resistance to that happening?

Mr McGowan: As far as I can tell, the sky hasn't fallen in, although last weekend it got pretty close. It was implemented a month or two back. The information has gone up on the web. Admittedly, that doesn't provide access for everybody, because not everyone has access to the web. We all know about the digital divide. There is information up there. I haven't heard a whole lot of complaining within the system.

THE CHAIR: As a supplementary: wouldn't one of the problems be that if I, as a patient, go along to my GP and he says I need a particular procedure, and I think Dr McGowan is very good in this area of orthopaedics or whatever the procedure is, do you envisage that I am going to, as a patient, go to the net and say, "He is very popular and is very busy; I will go to somebody who doesn't seem to be attracting as much work," or are you more likely, in reality, to say, "My GP says that Dr McGowan is the person to do this. It is a long wait, but he must be very good because he is in demand"? Isn't the reality that you, as a patient, I suspect, are probably not ultimately—you could—going to exercise a lot of control over the specialist that you end up with?

Mr McGowan: That all depends on your expertise as a patient and your experience as a patient.

THE CHAIR: In the main, do you think most people are going to do that?

Mr McGowan: I am going to do that and I am going to make the trade-off.

THE CHAIR: I suggest you might be a bit more experienced in this area.

Mr McGowan: Exactly, but we are encouraging other people—we are encouraging health literacy, I guess—to know what is available. Many of the procedures that people undertake aren't as necessary as they think they are.

MS MacDONALD: You talk about Dr X having a waiting time of nine months, and Dr Y having a waiting time of two months. How much of the health literacy and comprehension on the part of the consumer comes into play in terms of the demand for that doctor's expertise and their experience? Maybe they are better at the procedure, and

that is why they have a longer waiting list.

Mr McGowan: It could be. It could be that Dr Y has only moved to the ACT recently. It could be that there is a referral pattern of GPs to a particular doctor at a particular place because they are familiar with it. The other doctor hasn't had time to build that same confidence. It doesn't necessarily mean that Dr Y is not as efficient. He or she may be more efficient, which is the reason why their waiting times are lower.

THE CHAIR: That assumption which Ms MacDonald is putting could be quite widespread.

MS MacDONALD: It could be quite widespread. Dare I mention a little bit of—I don't want to be sexist here, but I will be—the old boys network: “I am going to refer you to my mate Dr X because I know Dr X. I went through medical school with him”?

Mr McGowan: That is what I just said. There is a network. We know that there are networks that operate, not just in this jurisdiction but elsewhere, which are not necessarily taking the patients' circumstances as the primary focus but more the comfort of dealing with a particular hospital or a particular surgeon.

MS MacDONALD: You talked about running the system for the sake of the health care consumers—

Mr McGowan: Patient-centred health care, I said. Person-centred health care might be a better term.

MS MacDONALD: I know that there are many good doctors out there who try to do that. There are doctors out there who would not necessarily be so inclined towards it.

Mr McGowan: It is not necessarily the doctors; it is the system which often mitigates against that. It is the way we organise the system without letting people know what the alternatives are. If you try to build it around providing the best fit, you are going to have fewer cancellations. I am sure the bane of most surgeon-proceduralists' life is the patient that doesn't show for a procedure—but at the last minute so that they don't have a chance to put somebody else in. It may well be that, if they talked to the patient, communicated appropriately with the patient in advance, they would have known that there was a prospect of a no-show and have been able to organise an alternative time for that patient.

I got rung up today by one of the specialists I see—I see nearly every specialist in town, so I am an expert in this field—who asked whether or not I would be prepared to shift my next appointment to another time to accommodate another patient. I was more than happy to do that. It is a matter of having the right relationship and communication channels to enable the system to look at the best fit which will achieve more efficient resources. As I say, they seem to have been able to do that in the UK. That is largely a public system.

MS MacDONALD: I had to undergo surgery a couple of years back. In the lead-up to it, we weren't sure exactly how long it would take because there were a certain number of things I had to go through before I was ready. That was very closely monitored by my

specialist. “We are not going to put you in until such time as you are ready to go in.” I am pretty sure she does that for all of her patients. It seems to be sensible.

Mr McGowan: That is what I am saying. If those communications are the norm rather than, as now, a bit haphazard—

DR FOSKEY: How can we, as consumers, know by looking at the internet site? I know you are not resourced to do this, but are you able to give anecdotal information about specialists if somebody were to ring up your organisation?

Mr McGowan: No. We would refer them to the net.

THE CHAIR: There is no risk in that.

Mr McGowan: We would not do that. There are ways of encouraging people to understand how to interpret the data that is there. This is a much broader thing, but we would be supportive of the bringing into the system of what has sometimes been called a care coordinator or a patient navigator, somebody who can help somebody steer their way through the health system, particularly if they have got a complex condition like cancer or a heart condition or whatever, which is going to involve multiple interventions over a period of time. It is very important to get those connected and not allow waiting lists to get in the way of those things.

THE CHAIR: Have you any knowledge of other jurisdictions, not necessarily in Australia but maybe overseas, where they do a better job of communication? I, touch wood, haven’t had much cause to use medical services, but as a parent of four children you find yourself in hospitals quite regularly, with sporting injuries or whatever. The way in which hospitals fail to communicate with patients or carers if they are a parent is a universal frustration.

I share the sentiment you expressed at the commencement of your evidence that it would do an enormous amount of good if people were given some indication of what is going on or what the time frame might be. Have you seen or are you aware of any examples where they have given greater weight to that to try to ensure that the patient is in the loop?

Mr McGowan: The two I mentioned in the submission were the UK, with the programming of actual things well in advance, and New Zealand, where they do this primary care review to constantly monitor the position of the person within the categories of the waiting list.

THE CHAIR: Our committee, obviously, is looking at the waiting list issue, but it is even broader than the elective surgery situation. It seems to be a bit of a cultural approach in hospitals that they don’t put much weight on dealing with the less informed and the less educated patients who may not understand.

Mr McGowan: There are some improvements. Australia is doing some good work in this area generally. It is an evolving process. There are national service improvement frameworks in each of the national health priority areas. These set out the progress that is expected for somebody through the health system when they have an identifiable need.

They certainly identify critical intervention points or the addition of resources that will try to make the patient's journey easier through the system. As these gradually get rolled out, we will get a better performance by the health system and fewer of these hiccups.

THE CHAIR: It is slow progress.

Mr McGowan: It is a slow process.

THE CHAIR: I and, I am sure, my colleagues have found this a most interesting and very considered submission. I appreciate you giving your time today for that further discussion before our committee.

Mr McGowan: Thank you.

The committee adjourned at 2.39 pm.