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Official Committee Hansard

**HOUSE OF
REPRESENTATIVES**

STANDING COMMITTEE ON HEALTH AND AGEING

Late effects of polio

FRIDAY, 30 MARCH 2012

MELBOURNE

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**HOUSE OF REPRESENTATIVES
STANDING COMMITTEE ON HEALTH AND AGEING**

Friday, 30 March 2012

Members in attendance: Mr Coulton, Mr Georganas, Ms Hall and Mr Irons

Terms of reference for the inquiry:

To inquire into and report on:
Late effects of polio

WITNESSES

BOOTH, Mr Mark, First Assistant Secretary, Department of Health and Ageing 1

de GRAAFF, Dr Stephen, Private capacity 1

DOBSON, Mr Arthur, Secretary/Public Officer, Post Polio Network – Tasmania Inc..... 1

DORAN, Mr Alan John Blaise, Coordinator and Physiotherapist, Polio Services Victoria 1

HOWARD, Mr Brett Ian, President, Polio SA Inc. 1

LIETHOF, Ms Mary-ann, National Program Manager, Polio Australia Inc. 1

PEEL, Dr Margaret Mary, on behalf of the Spinal Injuries Association (Queensland) and Polio Australia Inc..... 1

TELFORD, Ms Elizabeth, President, Post Polio Victoria Inc. 1

THOMAS, Ms Gillian, President, Polio Australia Inc..... 1

TIERNEY, Dr John W, OAM, National Patron, Polio Australia Inc. 1

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TIERNEY, Dr John W, OAM, National Patron, Polio Australia Inc.

Committee met at 10:06

CHAIR (Mr S Georganas): I declare open this public roundtable on the late effects of polio, sometimes also referred to as post-polio syndrome. Firstly, I will take the opportunity to welcome all the participants and to thank all of you for making the time to come here and speak with the committee. I also welcome those who have come to observe, in what we call the gallery. Late onset polio has been raised as topic of interest for the committee, hence today's roundtable and today's meeting. In fact, I note that two of my committee colleagues, Jill Hall and Mark Coulton, have some familiarity already as both parliamentarians and patrons of Polio Australia. Today's roundtable discussion will give the committee the opportunity to learn more about these issues and its impact on the lives of sufferers, but participants will have the opportunity to explore a range of issues. The roundtable format has been selected to facilitate an interactive discussion and a very laid back discussion. It is very informal. Participants have been provided with background papers relating to the issue that we are discussing today, The papers have been prepared by Polio Australia and highlight a range of issues relating to the discussions we are going to have. A participant paper prepared by the committee to guide discussions has also been circulated to everyone.

Today's roundtable will comprise an introductory presentation provided by Gillian Thomas, President of Polio Australia. This will be followed over the course of the day by three interactive sessions. The sessions are based around three key topics: definition and prevalence of diagnosis, management, and supports and services. All participants should have familiarised themselves with the guidelines for the conduct of the roundtable, which are contained in the participant paper. At this point, I should also advise that, although the committee does not require you to speak under oath, you should all understand that this forum is a formal proceeding of the Commonwealth parliament. Giving false or misleading evidence is a serious matter and may be regarded as a contempt of parliament.

Before we go to introductions, I need one of the committee members to move that we allow media in if it is the wish of the committee.

Ms HALL: Moved that way.

CHAIR: Secondly, someone has requested to take photos for Polio Australia and I ask the participants if that is okay. So moved by Mark Coulton and seconded by Steve Irons.

Ms HALL: My grandfather suffered from polio before I was born. I really became interested in this cause when a constituent in my electorate contacted me and I then started to realise the impact it was having in the community and how it was not being recognised.

Mr COULTON: I am very excited. Hopefully today will shed some light on the enormity of the issue and maybe we could start to indicate some paths that might be taken to alleviate some of the problems. I would like to congratulate this hardy band of campaigners that have been working towards this day for quite a few years.

Ms Thomas: I am the President of Polio Australia. I am also the President of Polio New South Wales. I contracted polio in 1950 as a baby, five years before the vaccines became available. I have been involved with Polio New South Wales since 1988 and with Polio Australia since it was established in 2008.

Ms Liethof: I am the National Program Manager for Polio Australia. I started the office of Polio Australia at the beginning of January 2010. Prior to that I was working as a polio community officer for Polio Network Victoria. I have been working with the polio community since 2004 and I am a community development worker.

Dr Tierney: I am the national patron of Polio Australia. I am currently New South Wales rep on the national executive as Vice President of Polio New South Wales. I contracted polio at birth in 1946, 10 years before the vaccines. I noticed the first symptoms of the late effects of polio in 1994. After leaving parliament in 2005, I was a partner at Government Relations Australia, which is Australia's leading and largest bipartisan lobbying firm but I also did some pro bono lobbying for a number of community charities including Polio Australia and Polio New South Wales, which I have become increasingly involved with over the last five years.

Over the last 18 years, I have taught myself to self manage this condition to try and slow down the relentless march of the late effects of polio.

In recent years I have attended various seminars on this around Australia and in Copenhagen and in Warm Springs, Georgia. This knowledge and skill gained in conjunction with regular treatments by an osteopath and also with a series of hydrotherapy exercises has enabled me to keep going physically right up to the age of 65, which is a normal retirement age. I will finish by saying that what is absolutely vital is that other Australians be able to develop these skills, stay out of hospitals and actually manage their own condition.

Mr Howard: I was born in South Australia in 1948 and was about five when I contracted polio. I was able to complete an apprenticeship as a toolmaker. In about 2006 I just got too weak to continue and with a little bit of arthritis as well I was not able to do too much at all. After some hydrotherapy and physiotherapy I was able to look after myself from 2007. In 2007 I joined Polio SA and was installed as acting president of that organisation. In 2010 I was elected in my own right and I have been in that position since then.

Mr Doran: I am the coordinator and physiotherapist for Polio Services Victoria, which is based at St Vincent's Hospital in Melbourne. Polio Services Victoria provides a state-wide service funded by the Victorian government Department of Health. My clinical experience is primarily in neurological physiotherapy and I started working with the polio population in Victoria about a year ago.

Mr Booth: I head up the primary health-care division at the Department of Health and Ageing in Canberra. I should say that I am not an expert in this area and I should, certainly for the first couple of topics, be doing a lot of listening to the experts around the table. I was asked to come along and talk about changes in primary health-care that are being done across Australia at the Commonwealth level, in particular things like the development of Medicare Local, the development of a primary health-care strategy and policy directions to move the health system away from acute focus to more chronic disease focus. So I will contribute more to that in the final topic session of the day, I think.

Mr Dobson: I am vice-president of Polio Australia and Tasmanian official secretary, in an acting capacity now because I have had to resign through my own health from secretary of the Tasmanian network. Because no-one else is doing it, I am still doing it in an acting capacity. I got polio when I lived on the family farm back in 1952. I call a spade a bloody shovel, so I hope you will put up with me. I suffered the onset of delayed effects of polio when an oesophageal hernia operation was bungled in a public hospital and they had to open me up again and put me on life support for three days. During that time my damaged motor neuron system just seem to say, 'I'm sick of fighting for you,' and I started losing my fine motor skills. I am dominantly left-handed and all that side of my hand is still semi-numb. My whole motor neuron system just seems to be shutting down. I was a musician for 40 years playing piano and organ. I cannot do it anymore, only for a limited time and only sometimes. I am getting so frustrated, but because I am me I am helping other people and I find it very rewarding. But I just cannot keep on doing it because my own body and brain are shutting down.

Dr Peel: I am secretary of the Brisbane Post Polio Support Network and I am here officially representing the Spinal Injuries Association in Queensland, which is an umbrella group that includes the post polio support networks.

I contracted polio in 1951 in Far North Queensland, and I developed post-polio syndrome in 1999. I was working at the time at the Microbiological Diagnostic Unit in Public Health Microbiology at the University of Melbourne. I found that I had to retire earlier than I expected, by about six years, because of the onset of post-polio syndrome. I am also one of two Queensland representatives on Polio Australia's Committee of Management.

Ms Telford: I am Elizabeth Telford and I am here as president of Post Polio Victoria. I am representing the experiences of the polio survivors who are members of our group, many of whom are here. I do not want to go over my biographical details but I do want to say that Post Polio Victoria has grown from a small group of five to over 100 members in just over a year, which I think reflects the needs of people and how passionately people are

feeling about having something done not just for us but also for future generations, because there are more people coming in who have polio. We have been told by one private orthotist that he has 150 people under the age of 30 on his books, so there are quite a few.

There are many of us who are in the prime of our lives and who are having to retire early and deal with the sorts of issues that you will be hearing more about today, and I have gathered a whole lot of stories which I will be presenting. I contracted polio in 1956, just before the vaccine came out, and developed post-polio issues around the age of 45. I have had to make enormous modifications to my life. I attended the Warm Springs conference and the Copenhagen conference so I am also bringing into this my global perspective.

CHAIR: Thank you very much. A *Hansard* will be produced for those who wish to go back and read the transcript. I now introduce Ms Gillian Thomas, President of Polio Australia. Ms Thomas will provide a general background on the issue of the late effects of polio and post-polio syndrome.

Ms Thomas: Thank you very much. Before I start, I want to mention that Dr Steve de Graaff will also be joining us as a witness later on. He is flying in from Tasmania this morning. I would like to talk about Australia's polio challenge, which is a challenge for polio survivors and the families and carers of polio survivors and a challenge for health professionals of all types.

In Australia during the 20th century polio was a very commonly contracted disease. There were lots of epidemics and huge numbers of people caught polio, and that is something that is not as well known as it should be. If we break up the infection rate: 89 per cent of people were unaware that they had been infected, or it was thought they just had a mild tummy upset and were not expected to be affected long term, if they even knew that they had it; 10 per cent appeared to recover in the short term, with no obvious resultant disability; one per cent did not recover in the short term and were left with varying degrees of paralysis, from something like a limp to spending the next 60-odd years in an iron lung; and 0.1 per cent died due to respiratory involvement.

The one per cent of polio survivors who did not recover in the short term who were left with varying degrees of paralysis are referred to as having contracted paralytic polio. Between the 1930s and the 1960s, 40,000 Australians contracted paralytic polio. Paralytic polio is not a separate strain of polio; it is polio. Some of the discussion in the literature about polio can be confusing because often the term 'polio' is only referring to paralytic polio, but that is actually only one per cent of the actual number of people with polio who exist in Australia today.

So, while some polio patients appeared to recover, and the diagnosis for them was probably non-paralytic polio, in reality they still had neurological impairment. This might have been minor; it might have been major. There is a whole spectrum. Basically, paralysis is only visible if 50 per cent of the motor neurons are killed off or damaged by the polio virus attacking them. Also, muscle weakness may not be perceived if it is balanced. For example, if both legs are weak then you do not actually perceive that one leg is weaker because of the polio; they are both weaker because of the polio but you have got nothing to compare it against.

This is a graphic of the nasty little polio virus in No. 1, up there in the top corner. It attacks the motor neurone. In slide No. 3, the infected neurone is the one that has turned grey. It then loses its connection to the motor neurone. The dark red part is the muscle. There is no motor neurone to drive that muscle, so the muscle becomes paralysed, temporarily or permanently. During the recovery phase, which is in about the first six months or so, other sprouts are sent out from additional motor neurones, surrounding motor neurones, and they actually grow a lot bigger than they were ever intended to be. They are doing a lot more work than they were ever intended to do. But the benefit of them sending out extra sprouts to these orphan muscles is that people got movement back and they apparently got over their initial paralysis. So people say, 'Well, I had polio but I got over it.' Then later on they found out that in fact they did not get over it. This is where the late effects of polio come in.

A polio survivor who has new symptoms—which I will go into in a minute—has the late effects of polio. There are biomechanical symptoms. Because we have had weak muscles pulling against strong muscles, because some muscles were affected and some were not, we have got a strange gait. You see us walking around, rocking from side to side. We have biomechanical problems, so we have joint pain and muscle pain and whatever. Dr de Graaff will go into that in a lot more detail.

We also have neurological symptoms. The neurological symptoms are really the post-polio syndrome component of the late effects of polio. You can think of it being that everybody will have some neurological symptoms, on a continuum from a lot to a little, and everybody will have some biomechanical symptoms on that same continuum, from a lot to a little.

The biomechanical symptoms are normally expected to occur because of the longstanding weakness. So that is muscle and joint pain, fatigue, osteoporosis, arthritis, scoliosis or kyphosis, which is curvature of the spine—either this way or that way—an increase in falls, weight gain and a very pronounced age related weakness, which

comes on earlier than expected. Obviously, Dr de Graaff will go into that in more detail. Blaise will as well, of course.

The neurological symptoms of post-polio syndrome include new muscle weakness, muscle and joint pain, fatigue unrelated to activity, muscle wasting atrophy, heat or cold intolerance, swallowing, breathing or sleep disturbance, and muscle twitching and fasciculation. Some of those symptoms cross over with the biomechanical symptoms as well.

This slide is showing you what happens with post-polio syndrome. In the earlier slide there was the neurone sending out extra sprouts, but now they are starting to die off. One theory is that they are dying off because they were bigger and doing a lot more work than they were intended to. Overlaid on that is the normal ageing process, where we lose them as we age anyway. So we have the double whammy, if you like. The ones that were doing too much work are dying off, plus we are losing them due to ageing.

So who is affected? Back in the dark ages, in the eighties, they were saying that only patients who had had paralytic polio could be affected by the late effects or by post-polio syndrome. But these couple of slides show that quite a lot of research has now happened and articles have appeared in peer-reviewed journals, especially in America, about the fact that people who had non-paralytic polio are also experiencing the effects. There is some more on this slide. Lauro Halstead is a very well respected polio expert in America, and there are some other references there. We have copies of all the slides, if anybody wants to see the references.

There are a lot of gaps in research. There is not a lot of research going on—in Australia, very little or none. There is some going on in America. There was a Cochrane Collaboration in 2011 which indicates that some pharmacological solutions may be possible. Muscle strengthening exercise might be part of it, but they need a lot more work. The next slide has a lot on it, but it is actually the outcomes of the Copenhagen conference. It is saying that the most promising area focuses on the role of inflammatory factors. That might be something that can be looked into.

High-quality research into the effectiveness of pharmacological and rehabilitation interventions are needed. Research interest needs to increase. Unfortunately, around the world polio survivors are treated like, 'Well, they're all dying off, so we don't really need to worry about it.' But, in fact, we are still here and we are going to be here for quite some time to come. Research needs to happen. Polio is not a disease of the past. It is still in several countries in the world and obviously there are going to be whole new generations of people coming through with the late effects of polio. We cannot just ignore it.

As to the impact of late effects, I broke up these into 'At home' and 'At work'. These are extracts from some case studies we have gathered over the years. It has a huge impact on how you actually cope with the activities of daily living. With your family and personal relationships, everybody is used to dad or mum being able to operate at a certain level and now dad or mum cannot operate at that level anymore. It can really affect relationships. It obviously can affect your independence and your self-esteem. As this person says in the second quote, he was very angry at doctors who dismissed his pain and spasming as psychosomatic and not a medical condition. A really common problem we have is actually getting doctors to understand that we do really have a medical condition.

At work, people have found that they are possibly no longer able to work full-time. As Margaret said, she had to retire several years earlier than she expected. I also semi-retired quite early, earlier than I expected I would have to.

It becomes difficult for people to stay working and often they do not want to reveal that they are having these problems because of—looking at the next slide—the financial impact. If they have to give up work then obviously they are reducing their financial independence. Of course, as far as the government is concerned there is the possibility of earlier government income support being required for pensions et cetera. So polio survivors may need to do a whole range of things in their work places, all of which will have financial implications for them.

The resources that are needed to manage the late effects of polio are quite extensive. It is a multidisciplinary team. I am not going to go into details on all of the top ones because, obviously, that is not my area of expertise, but Dr de Graaff and Mr Doran will certainly go into all those areas. I am going to concentrate more on the polio support groups. The 1980s was really when news of it first came into Australia. Some Australian polio survivors went over to America in 1987 and, following that, polio networks were established in each state. Here is a picture of some people in a support group. The peer support and the shared information has greatly assisted polio survivors. It has been done pretty much on a volunteer level all around Australia. There has been very little paid support work like Mary-ann used to do in Victoria.

To give you a quick rundown on the state networks, the Post-Polio Network NSW is self-funded and has three part-time staff and 25 support groups. It gets its money only from membership fees and some ad hoc philanthropic funding. New South Wales has been going since 1989, as has Polio Network Victoria, which has one part-time staff member and, as you can see, a number of support groups. Post Polio Victoria is a volunteer run advocacy service and was established only last year. Tasmania is, again, volunteer run, with three support groups. It was established in 1998. There was an earlier group in Tasmania, but it did not continue and then the new one started. Polio South Australia, of which Brett is the president, is another volunteer run service with a few support groups. They do actually get a little bit of money from their state department of community services. Western Australia has one paid staff member but is otherwise run by volunteers. They have a registered nurse run a clinic over in Western Australia. It was established in 1989. Queensland, represented by Margaret, has the Spinal Injuries Association. They have four staff and 18 support groups, but only six are for polio and the money that goes into those positions does not all therefore go towards polio. In the ACT there is a support group only, which is part of Polio NSW. There is no staffing or office. In the Northern Territory there are no support groups, although individual polio survivors are members of the South Australian and New South Wales networks.

In 2007 all the state networks got together, had a conference and resolved at that conference to form Polio Australia, which was incorporated in 2008. The main objectives of Polio Australia are to do what we are doing here today: articulating the needs of polio survivors to provide consistent and central information and develop some education and training programs, not only for the polio community but to help health professionals as well. Of course, we have to have a mission and vision. I will not read that out. The key programs are self-management residentials. We conducted the first one in 2010 in New South Wales. These have all been done with philanthropic funding. The program went for three days, each day focused on a theme and the themes were body, mind and spirit, with the aim of finding a holistic approach to managing the late effects of polio. It was based on one that was held in Warm Springs, in Georgia in the United States, which a number of people around this table attended. Last year we went to Victoria for the self management and next month in a few weeks time we will be up in Queensland, holding the third one.

Our next key program is the Australian Polio Register, which was established in October 2010. It is a capturing a range of details, including a few interesting points, including that 16 per cent of the people on the register at the moment actually contracted polio outside of Australia. They are on top of that 40,000 paralytic plus all the rest of them, the other 99 per cent. A number of these 16 per cent who contracted polio outside of Australia are of course the younger polio survivors, who are migrants coming into the country. Eighteen per cent were not hospitalised and six per cent do not know whether they were or not, so about 25 per cent or so of people may not have actually been diagnosed with polio in the first place. That leads to a lot of underreporting of polio numbers. We are obviously encouraging people to sign up to the register, but we are doing it all on a shoe string and on a volunteer basis.

The third key program is the clinical advisory group. Dr de Graaff is on that. It includes a range of health professionals, who cover lots of different areas, such as rehab, physio, orthotics, psychology, respiratory and research. That is a few of their mug shots up the top of the screen. They are tasked with standardising quality information and producing resources for health professionals and for the polio community. However, as I said, that is also done on a shoestring; resources are needed to achieve that. We are confident that the intervention of the work that they are doing will keep people out of acute care facilities. That is really a big thing, because obviously they are very expensive.

Where to from here? Obviously we are here at this roundtable and we are very grateful that this committee is taking our problems seriously and is taking evidence from the range of experts. We are looking forward to the committee report being released. Our bottom line is that we would like the late effects of polio to be recognised as a substantial and urgent national health concern, and that diagnosis, management and support will become readily available across Australia for polio survivors, whether they are younger or older. Thank you very much.

CHAIR: Thank you very much, Ms Thomas, for backgrounding the committee with that information and giving us a bit of an understanding of polio here in Australia and in fact a bit of a global perspective as well, from those figures that you gave us. The next session will be the topic of definition, prevalence and diagnosis of the late effects of polio and post-polio syndrome. We will be conducting an interactive roundtable session. We will hand over to you for a five-minute briefing to us on that particular topic and we will go through each person. If you do not wish to give a statement, you do not have to. Just indicate and we will go onto the next participant. Members of the committee: whilst the presentations are being given, if you want something clarified—not a question; a clarification of anything—raise your hand and we will ask for that clarification. We will take questions at the end, when everyone has completed their five-minute statement. I think that we may start.

Ms HALL: Seeing as a lot of the people around the table are suffering from the late effects of polio, they may like to have a stand and a stretch before we move to the next part of proceedings.

CHAIR: Yes, that is a good idea. Let's have a quick break before we proceed.

Ms Liethof: I am the National Program Manager and only employee of Polio Australia. In 2008 I had a Churchill Fellowship to study post-polio and I travelled over to North America. I visited 10 post-polio institutes while I was there, and they have the same problems that we do when thinking of what the prevalence of the late effects of polio are in their post-polio community. They commissioned a report in 2006 and it came up with the same sorts of vagaries that we are experiencing now.

We have been looking to get some kind of research into the numbers of polio survivors in Australia. We are having the same issues. They were everything that Gillian was talking about before—the fact that some people were not hospitalised; they did not actually know that they had had polio as children. A lot of people have passed away in that time, because the only figures that we can work with are of people who had polio between the 1930s and the 1960s, when the vaccine virtually dried it up, which was a very good thing. But it is difficult to narrow down the people that may have passed away versus the migrant population that has come in since then and try and say: 'How many polio survivors are we talking about?' A study was done by a woman by the name of Charlotte Leboeuf in 1991, and she identified that there would be about 40,000 people who contracted paralytic polio between the 1930s and the 1960s. However, that is paralytic polio, and we know that that is only one per cent of all polio infections that occurred in those years.

I have received other information since, from both the United States and Denmark. When we were at the Copenhagen conference, I went to the PTU, which is an organisation that works with polio survivors. They have, I think, about 1,300 people on their books and 60 staff to look after them, which is just amazing, and that would definitely be a benchmark that we would like to work towards. They say that about 10 per cent of the people they are working with are migrants and younger polio survivors.

So all we can indicate at this point is that there may be anything up to hundreds of thousands of polio survivors living with the late effects of polio in Australia today. We have managed to get the interest of the Australian National University's epidemiology department. There is a woman who is doing her master's there and she is doing a bit of number crunching for us, but we know that the numbers that we have been able to get have all been a little bit flaky—well, not flaky; it is just that the records were not kept well and hospitals came and went. I have had untold numbers of people ringing me up asking where they can get their hospital records for their polio, and they just do not exist. Some have been able to get it, but the majority of people have not been able to get that sort of information.

It is very difficult to track that down unless we can really ramp up the information on the Australian Polio Register, get a bit of a campaign happening and get that out to the general public to say, 'Please sign up to the Australian Polio Register,' so at least it will give some kind of indication of what the prevalence is. We are never going to get exact numbers.

Mr Doran: Some of this has been covered in the presentation but I will speak from the perspective of Polio Services Victoria as that is the one I can really give you. Diagnosis is made usually on a very thorough history. But the problem with that is that some of the histories are relatively sketchy, as we have just been hearing, and with the passage of time that gets worse. A distinction is usually made between the late effects of polio syndrome and post-polio syndrome although, as we have heard, the two can coexist quite easily. I am going to give definitions that are, I suppose, somewhat technical but they will give you an idea of how most clinicians approach what are essentially long-term chronic health conditions.

The late effects of polio are, as we have heard, much more associated with biomechanical problems. That comes from a highly compensated neuro-musculoskeletal system. So all those things go towards having a problem with things and I suppose the foremost problem would be the osteoarthritis that people complain about. The stress on joints tends to mean that people will develop osteoarthritis much quicker than you would expect in a normal ageing population. So with that goes pain of a mechanical and sometimes inflammatory nature. That said, neuropathic pain problems also occur as you can get nerves being pinched at the spinal level where they come out. That is relatively common.

So when we are talking about definitions we note the biomechanical side of things can give rise to all sorts of other secondary problems. You can get problems with general physical activity, in not being able to do things, which results in you having disuse muscle atrophy, which is superimposed on the already existing polio muscle atrophy; an increased incidence of things like osteopenia and osteoporosis, osteopenia being thought of as a precursor for osteoporosis; the reduced cardiovascular fitness that goes with being inactive; and respiratory

compromise, as we have heard, from progressing scoliosis, kyphosis and all that kind of stuff. Obesity is also a problem when you become inactive. So the ageing process does occur in the normal way but, obviously, as we have also heard, that has a much bigger impact on the polio survivor. It tends to be much more debilitating.

Post-polio syndrome presents in a much more neurological way. The best-fit hypothesis is that the ongoing process of denervation and reinnervation of the neuromuscular junction tends to arrive at a point where the denervation is no longer compensated for by the reinnervation. We have also heard that some European clinicians and researchers believe that it has a neuroinflammatory component. They are really looking into whether or not that of itself is part of post-polio syndrome.

The diagnostic criteria that were agreed back in 2000 by the March of Dimes conference on post-polio syndrome were published in 2001. They are essentially the standard diagnostic criteria for post-polio syndrome that people still use. I went to the Copenhagen conference last year as well. The clinicians there believed that those diagnostic criteria have essentially been validated. I cannot read those out in the time that I have been allotted but I have them available if people want them. In my own opinion and experience, all polio survivors, to a greater or lesser extent, will have the late effects of polio, the biomechanical ones. It is about whether or not all that affects them, and whether or not they report that is a completely different matter.

Prevalence is a much more difficult question to answer. The literature suggests between 25 and 50 per cent, which is probably accurate given my clinical experience. In the Australian population I think one of the major issues about the epidemiological data is knowing what we are having to deal with and the health economic costs, not just the fact that we just do not know how many there are. The age group that we predominantly deal with is those between 59 and 79 years of age. There are big groups either side of those age groups. But that implies a further 20 years worth of support for that group alone.

Mr Dobson: In Tasmania in 1937-38 we had the second-worst epidemic the world has experienced. Some years later Iceland had a higher figure per capita. Most of our members are around the age of 80 now. Quite a few were told when they were kids: 'Don't you dare let on that it was polio. Don't you even think it was polio.' Polio was a dirty word. Their parents went to their graves making these people promise they would never admit it, but, as these people have aged and with the medical examinations they have had, polio is the only possible explanation for what happened to them. Tasmania, compared to the mainland, is a small place and there are very isolated pockets in the rural areas. One only has to look through the cemeteries in some of these isolated areas to see the graves and that the age of death occurred at the time of the worst epidemic. So a lot of those deaths were never diagnosed as polio. It is only through word-of-mouth or if the church records still exist, because the doctor would never have got to see the person before they passed away. They would have been just quietly buried in the country churchyard. There may have been something written in the church records, but a lot of those churches were destroyed over the years through fire et cetera.

The point I am trying to make is that the underreporting of the cases of polio is unimaginable. It is very difficult. I find it hard to come up with any sort of realistic figure. The whole thing spread and no-one knows why. No-one knows why I got it on the farm 20 miles out of Launceston when there was no-one around who had it. It must have come via a commercial traveller or the returned milk cans from the city when we were supplying milk for the town supply. Perhaps the bug got on the milk can somehow. We do not know. This is where the underreporting of cases is unimaginable. It makes it very hard to come up with true figures on how many people were affected.

CHAIR: Thank you very much.

Dr Peel: I would like to make a point with regard to the definitions of late effects of polio and post-polio syndrome. Much of the overseas research literature does not report on late effects; rather, they usually call the condition 'post-polio syndrome'. For example, the Karolinska Institute in Sweden has a long list of research publications—some 25 or so—and you will not find the term 'late effects of polio' in the titles of any of those publications. That is one point to make. The research, as we have already indicated, might be inadequate but, nonetheless, research does occur in North America, particularly in Canada at the Montreal Post-Polio Clinic, and also in Europe. As I have already mentioned, there is the Karolinska Institute in Sweden. Also, a lot of the research comes from the Academic Medical Centre in Amsterdam. The Danish Society of Polio and Accident Victims is another source of considerable research.

Generally speaking, the term used in the research is 'post-polio syndrome'. The Karolinska Institute defined post-polio syndrome in a recent publication, in 2010.

According to their definition, it is based on what they called a triad of simply pain, muscle weakness and fatigue. You find this kind of difference in the definition between Australian and overseas research publications.

Ms Telford: I want to make two comments. One is about the consequences of misdiagnosis of post-polio syndrome or late effects of polio. Firstly, my own experience when I was 45 and beginning to have symptoms, I was diagnosed as having fibromyalgia, menopause, depression and anxiety. Over about six or eight years, I was being diagnosed with all these things. That is just one person. That had huge consequences and made the situation much worse, and I have got many other stories from other people that are very similar.

I had a very good GP, but there is an absolute lack of community awareness. Polio Australia and Post Polio Victoria and General Practice Victoria last week had a first and held a session for general practitioners. We had about 14 GPs, some practice nurses and others. The feedback was very positive but what we heard from them was that they did not know anything about post polio and had nothing in their training. So that is clearly an area where there needs to be some development.

There is also a lack of community awareness and that includes polio survivors. I did not know what was going on with me. We do not turn up to the GP and say, 'We are having post-polio problems.' It was not what I was thinking.

The second point is about the impacts of all of this on survivors. We have talked about the physical but there are financial, social, emotional and physical effects. These are all interconnected. The financial impact, as we have heard, can result in early retirement. I have got a number of cases here from last week of people who had to retire 15 years earlier and that has impacts on their financial planning. There is discrimination in the workplace—one person told me about an accessible toilet but it was used as a storeroom. Being disconnected from your workplace or the community has huge impacts.

The costs include assistive devices, braces, back braces, wheelchairs, scooters, CPAP machines—you may need all of these things at the same time. People in our group, including me, have a number of different assistive devices. I walk with crutches and I have a brace. I have \$3,000 on my right leg. I also have a scooter, which was about \$3,000, and a wheelchair. I have all these different things to enable me to continue to do the things that I did before. I have a brace to enable me to swim in the water, which was \$1,500.

We have SWEP—the state-wide equipment program—in Victoria, which allows up to \$2,200 for devices. Most of the stories that I have are about people being on the waiting list and being on the waiting list in a public system because there is no ability or funds for it. People are often referred because PSV is a consultation service often referred to private orthotists. We can spend up to \$10,000 or \$15,000 in a year and get maximum \$2,200 back. The point I want to make about that is that it has a huge impact on us socially and emotionally and on our ability to connect and maintain a level of independence, which is what we are all trying to do.

CHAIR: Thank you very much for those statements.

Dr Tierney: We have been talking about misdiagnosis. I want to give a cameo of what happened to me, which was a misdiagnosis at a number of points. First of all, I contracted polio at birth. A doctor had attended a polio case and then came to deliver me, so we think he is the prime suspect. But it was not recognised at that point, even though I had a very high fever. People had a lot of knowledge of polio at that time but it still was not diagnosed. I was taken away for a few days, strung up at a certain angle, for breathing, but they still did not say it was polio. It was not until I started to try to walk; a doctor looked at it and said, 'Oh, he has old unrecognised polio.' So misdiagnosis occurred back then.

The next point was when I was lecturing at the university in my late 30s. I started getting incredibly tired. I would get to lunchtime and I would feel like it was time to go home. A specialist diagnosed me with chronic fatigue syndrome. But it was not chronic fatigue syndrome; it was the start of the late effects of polio. When it did start to get underway in my forties, it was incredibly hard to get accurate medical advice. If you saw a GP, no-one would say, 'You have the late effects of polio'; no-one ever said that. I just managed to get to a spinal specialist who did an MRI and looked at the spine and it was staring at him what was wrong. So, even though I had a high level of awareness of the condition, there were problems with the medical system all the way through, from birth up until recently.

CHAIR: Thank you.

Ms Thomas: I have another point about the diagnosis: you cannot go out and get a blood test that says, 'Yes, you have late effects of polio or post-polio syndrome.' It is a diagnosis of exclusion, so a doctor has to actually exclude everything else that it could possibly be before they can conclude that it is the late effects of polio or post-polio syndrome. The reason for that is fairly obvious; the major symptoms are fatigue, which is common to a lot of other diseases. So you have to be persistent to get the diagnosis.

I have talked to people who have been on the diagnosis roundabout for years and have not had it diagnosed. When they finally are diagnosed and it is found to be related to their polio, they are just so relieved that it has a

name. And then there is the expense of being on this roundabout—to the health budget as well as to the personal budget.

CHAIR: Thank you very much for those statements. It has given all of the committee a good background on what we are discussing here today—the issues, definition, prevalence and diagnosis. We will open up with a general discussion and questions.

I might start off with Dr Tierney, who spoke about being misdiagnosed with chronic fatigue syndrome. As Ms Thomas just said, we all feel tired or achy occasionally or think, 'I wish I could go home at 12 o'clock because I feel sleepy.' Many would be diagnosed with all sorts of things; chronic fatigue syndrome being the one that comes to mind immediately. In your situation, when you were diagnosed with chronic fatigue syndrome, how many years after that did they diagnose you with late effects of polio?

Dr Tierney: That was 1988. I got the MRI in 1994, six years later. I initiated that. No GP said, 'We will send you for an MRI and see what the problem is.' I thought it would be a good idea, so I did it.

CHAIR: That brings me to the next question, which is to Ms Elizabeth Telford. Ms Telford, how long was it before you were diagnosed from the time when you were not feeling too well to the actual diagnosis? I am trying to get an average of the length of time most people have to go through.

Ms Telford: My first symptoms and my first incorrect diagnosis were in 2000. It was 2007.

CHAIR: So, six or seven years. Is that about the average?

Ms Telford: Yes. A consequence of that also was that I was put on exercise programs that actually made me worse. I was being seen as deconditioned and was told that I needed to get fitter, and I was constantly re-injuring myself.

CHAIR: Can someone explain what the benefits would have been had you been diagnosed immediately? What would the different outcome have been?

Dr Tierney: If doctors were properly educated on what this condition is and how to manage it, I would have been given some information on how to manage the condition. I have educated myself over a long period of time on that. There are a lot of no-noes in this, things you should not do. You should not overstress the muscles. If you exercise, it has to be very gentle. Obviously, with hydrotherapy you are in water and it is very gentle. That is the way to keep yourself fit. But if people start doing weightlifting or going to the gym those very poor connections into the muscles then start collapsing at a faster rate, and you get muscle weakness moving towards paralysis if you undertake the wrong exercise regime. People need to be advised on that.

CHAIR: So the misdiagnosis for that period of, say, six or seven years—let us say the average is six years—is causing a lot more damage through different regimes of exercise. The benefit is in the management of the illness.

Dr Tierney: Yes. I will give you an example from the United States. When I went to the conference and retreat in Warm Springs I shared a room with a fellow who was a Latin teacher and, to relieve his stress from teaching high school Latin, he used to run marathons. This fellow had polio. By the time he got to 42 he could no longer teach, because he was physically unable. I met him when he was 47 and he had a whole lot of aids for moving and walking around. But he had accelerated that condition by possibly 10 or 20 years by doing the wrong sort of exercise.

Mr Doran: I think it is worth touching on the fact that, if you get an erroneous diagnosis at the start and it takes six to seven years to get a correct diagnosis, people have been through the hospital system, either through private health care or through the public system, many times trying to find a diagnosis that actually fits better than, say: 'You've got chronic fatigue syndrome' or 'You've got fibromyalgia.' That in itself costs the economy. It has to cost a lot of money, but we do not know what that money is because we do not know how many times people are going through that. There is no data being collected for that kind of health economic loss.

Mr IRONS: CFS gets priority and knowledge for doctors, and PPS does not. Doctors look straight for CFS instead of PPS.

Mr Doran: I cannot really comment on why doctors would necessarily choose that over another. What I can say is that the information about the late effects of polio and post-polio syndrome is out there. It is out there in various guises and it is out there also in nicely digested packages for GPs. Queensland Health published a fantastic document. It is still a fantastic document, and it was published in 2002. I constantly send that off to people either by web link or as physical paper copies and say, 'Have a look at this. Maybe you can start talking to your patient on this kind of level.'

Mr IRONS: Do you think it is because there is a perception in Australia that there are no problems with polio in Australia and doctors have the same perception?

Mr Doran: To be fair on the medical profession, due to the way in which medicine is taught these days you cannot teach everybody everything. It is impossible. So what they do is teach you how to find the information, how to evaluate that information and how to integrate that into your practice.

The problem possibly comes at that point: you have the skills but you have not sourced that information, evaluated it and integrated it into your practice. That might be because GPs in particular have a six minute consultation time. Perhaps you go for the best fit. I am not a GP so I cannot really comment.

Mr Dobson: My diagnosis came as a result of the loss of fine motor skills following the hernia operation I mentioned earlier. I was sent to a neurologist. He used a cattle prod—I think it is called an EMG—and I used some choice language when he had me bouncing off the bed like I had touched an electric fence! He was going up and down my arms and he was scratching his head. I said, 'I don't like to see you professional blokes looking so worried,' and he said, 'The nerves in your arms just don't make sense.' I mentioned to him that I had polio as a kid and he said, 'That's it. Where were you affected?' I said my legs were affected; I was in calipers for a few years. He said the polio had affected the nerves over my whole body.

CHAIR: He picked up on it straightaway.

Mr Dobson: He picked up on it straightaway. As I deteriorated and lost so much of the fine motor skills, thank goodness he was honest enough with me, and bright enough, to pick it up when he was there shaking his head.

CHAIR: How long was it from the time you were not feeling too well until the diagnosis?

Mr Dobson: It was only a matter of weeks. No-one could explain why I was losing my fine motor skills until I went to the neurologist. He was Tasmania's star neurologist and he was killed in a skiing accident in New Zealand. That gave me the evidence I needed. I have never questioned his diagnosis. A lot of other people have.

Ms Liethof: There has been a research paper put out by the British Polio Fellowship about how long it takes from onset to diagnosis, which is in fact six years.

CHAIR: Yes, we had two examples here.

Ms HALL: The thing that struck me this morning was the lag time between the late effects starting to become apparent and the actual diagnosis. So my questions are going to be around that issue. Is there a set protocol for diagnosing the late effects? Is there a set of diagnostic tools that doctors can be made aware of and can they be put in a position where they look to that rather than waiting to be told by somebody like John, who would be more likely than others to push for a diagnosis and ask for an MRI? Other people might not be as articulate or able to demand attention from the doctor as John is. Is there a procedure or protocol in place that doctors will immediately look to? If not, what needs to come out of today's roundtable so that we can recommend that and so that sufferers, when they go to the doctor for a consultation, are not just told it is chronic fatigue syndrome or polymyalgia or some other similar type of diagnosis? What do we need to put in place? What is there, and what do we need to do?

CHAIR: Who would like to answer that?

Ms HALL: Everyone can have a go.

Mr Doran: Dr Margaret Peel raised a very good point. The problem is partially that in the research literature post-polio syndrome is generally only used as the label.

The diagnostic criteria that most clinicians go by—and I say this because Dr Frans Nollet of the research group in the Netherlands stood up at the Copenhagen conference in 2011 and said we can now say, after 12 or so years, that the diagnostic criteria brought up at the March of Dimes International Conference on Post-Polio Syndrome has now been validated. The issue with that is that those diagnostic criteria are quite fluffy—fluffy being a technical word. I have them available to you if you would like to see them. They are available fairly readily in the literature. They are available by just looking up what the diagnostic criteria are.

Ms HALL: Could I ask you to table that to be part of the committee's evidence.

CHAIR: So moved by Ms Hall and seconded by Mr Irons that the committee will accept the papers as evidence.

Mr Doran: If we look at those diagnostic criteria, I could probably almost guarantee there will be some polio survivors saying, 'Well, that does not seem right,' because we are talking about paralytic polio mostly. There are some of those diagnostic criteria that have been modified slightly to include the caveat that there are some people who present with nonparalytic polio or very mild paralytic polio who may still present with similar symptoms. The issue is, if you want to tease apart what are the biomechanical problems and what are the neurological

problems, that some of them mimic each other. So you can get joint and muscle pain as a result of altered biomechanics and you can get joint and muscle pain as a result of neurological symptoms.

Yes, the diagnostic criteria are available is what I can say. Why don't clinicians use them? It depends. I still hear reports from patients who come to see us and come to see our service who say, 'My GP just does not believe me. My GP does not believe in post-polio syndrome.' I could understand that if it was a very contentious diagnosis but I cannot say that it is. It has been established for a very long time. It was first put forward in the early 1980s. We have moved on quite a number of years from then. Although the coalface of medicine and the allied health professions are sometimes slow to pick up on things, I think that 30 years is enough time now.

Ms HALL: Is further education needed of clinicians and allied health professionals?

Mr Doran: It comes back to the difficulty that those people who will be teaching allied health professionals and medics will say, 'We cannot include that. What we can do is teach you how to differentially diagnose; so, if you are confused about certain things, pursue the possibilities.' However, I think there could be more awareness.

Ms HALL: Where is the ray of sunshine?

Mr Doran: Where is the ray of sunshine? I think there are plenty of rays of sunshine. If I ruled the world, as it were, I would be using the superclinics that are being set up by the federal government as a point at which information could be disseminated, to start a campaign where you could say: did you have polio as a child? Please inform your GP.

CHAIR: At least ask the question.

Ms HALL: That is very simple.

Mr Doran: There was a poster campaign in the UK in GP surgeries asking the question about rheumatic fever. Did you have rheumatic fever as a child because it has long-term health implications if you did, so inform your GP.

Ms Telford: Something that would help would be for the inclusion of the number of polio survivors and whether they live with late effects of polio and PPS on the ABS chronic illness survey. I think that would help with the numbers. Of course, a lot of people may not think of their polio. I think there needs to be community educators employed for that very purpose: to educate not only the doctors and allied health professionals but also the general community.

Ms Liethof: The other thing that you asked, Jill, was what sort of things we could be looking at. Polio Services Victoria created a range of flyers that have been useful but that certainly—as I am sure Blaise would agree—need updating. We have got one for GPs that Queensland Health put out in 2002. But Polio Australia would like to see a range of practice modules, similar to something that MS Australia have put out and have online, called 'MS practice for health professionals'. They have got a range of conditions that are related to MS and health professionals can look at how to work with that particular condition. I would love to see a range of those modules be produced for the late effects of polio and post-polio syndrome. That is the type of thing that we would like to work with our clinical advisory group on so that that sort of information is available online for health professionals across Australia. A lot of information exists out there in the United States and in various parts of Europe. I think what we really need is something a bit more home-grown with some home-grown content and something that people can use which is an easy diagnostic tool and a clinical practice tool.

Mr Doran: Just to answer that, yes, Mary-ann is quite correct. We have a great deal of information available on the website. We provide that information regularly to both patients and clinicians. We point people in the right direction for the right kind of information, to try to make it easy for them. So I suppose if the information is actually out there, it is the catalyst that is needed to get people to look at that information and apply it.

CHAIR: What are the risks of self-diagnosis by the patient?

Mr Doran: Very few patients will self-diagnose. If patients self-diagnose we take that on board and say: 'Okay, that is fine. Come in and see us. Let's unpack what your problems are.' My consultations take quite a long time, for that very reason. Instead of me choosing to say, 'I will see you for an hour today and I will see you for an hour next week,' I might do all that in one go and see someone in 2½ hours.

CHAIR: Going back to diagnosing the polio, Mr Dobson was diagnosed pretty quickly because it was fairly extreme. Is there a test that can be done to show that someone has had polio in the past?

Mr Doran: Yes, usually through nerve conduction studies and EMG, you can confirm, by the pattern that is returned from that, that somebody has had anterior horn cell damage or damage at the spinal cord level which is consistent with polio.

CHAIR: Is that a difficult test to conduct or is it something that can be done pretty simply by going to your GP?

Mr Doran: It is not usually through your GP. It is usually through neurophysiological testing done at a major hospital.

Ms HALL: I wanted to link into the answer that both of you were giving a moment ago.

Mr Doran: About the catalyst to getting that information across to people?

Ms HALL: Yes. First of all, isn't it more likely that a person would be more inclined to ignore their symptoms or to put them down to something else? That is what I was hearing earlier. Could I have a comment on that. Also, could you table the modules that you were talking about? Perhaps they could be a prototype for the type of thing that needs to be developed for the late effects of polio.

CHAIR: Is it the wish of the committee to take that as an exhibit? There being no objection, it is so ordered.

Ms HALL: Earlier I was hearing people say, 'We ignored it. We tried to get on with it. We didn't know what it was.' I just need to get clear in my mind whether it is more common for people not to look towards the polio they had in the past for the problems they are having.

Dr Peel: It depends on how severe the symptoms are. My symptoms were sudden and were severe and warranted investigation. I had a painful right knee. That is more in the biomechanical side of the problems, because my right knee is my good knee. So it is all that overuse and dependence on that particular joint that has led to pain. I had pain in that knee for six months. So that needed investigation in my view. Also, I suddenly found I could not get out of bed in the morning without a chair beside my bed. Can you imagine it? I have been hopping out of bed every morning and going off to work and suddenly I had to have a chair to get out of the bed. Then I am falling for no good reason—not tripping, falling. So it was obvious to me that something was wrong.

I firstly went along to a sports medicine doctor. I thought he would be pretty good at knees. He had a model of a knee on his desk and I thought he would be even better at knees. He finally said to me, 'I have no idea why you have got a painful knee. There is no sign of arthritis. Not a Baker's cyst,' and so forth. That did not really take too long because I had been reading the medical literature, because I am a microbiologist. So I self-diagnosed at that point and then I approached Dr Stephen de Graaff to confirm my self-diagnosis. But, as I said, if the symptoms are sudden and quite severe, you feel they must warrant investigation.

CHAIR: Thank you. Ms Telford.

Ms Telford: I just wanted to add to that and pick up on the hidden side. I think it is true that many people do avoid confronting the symptoms. We have been brought up, having had a childhood disability, to try to keep up and minimise as best as we can. And then it gets to that point where we cannot do that any more. That is quite an emotional and psychological shift.

The other thing is that many people have had very traumatic experiences in hospital. Some have had experiences in hospital that were not traumatic but were not very pleasant, because we were children and babies. So going in and connecting with the medical profession is something that for some people is not desirable. There was another point I wanted to make, but it has gone.

CHAIR: When it comes back, let me know, and I will give you a call.

Mr COULTON: My apologies for being out of the room, Chair, and if this has been answered we will move on. With the misdiagnosis I recall from one of our previous conversations at another time that if late-onset polio is misdiagnosed as something else the treatment can actually exacerbate the problem of the polio and increase the rate of the disease taking hold. I am sorry if that has been covered while I have been out of the room. I am not sure whether Blaise or Dr Tierney might have a comment on that. I am wondering whether that is not one of the key issues.

Mr Doran: I think it can be an issue. I do not know what the figures would be for that in terms of when people receive an incorrect diagnosis. Part of the problem as well I suppose is that most people, when they go through some form of rehabilitation, the paradigm of rehabilitation is incremental; in other words, you get better—that is what we are trying to get you to do.

If you push somebody too hard and make them worse, you should really stop and think, 'What's going on there?' but some people miss those signs. I often say to the people who have met me and have been assessed by me—there are probably a few in the audience—that polio survivors have incredible mental stamina. What they do with that mental stamina is override the signs that things might be going wrong, because they have been used to doing that for most of their life. In particular, they override the fact that they might be feeling a little bit weak, they override the fact that they are absolutely exhausted, and they override the fact that they are in pain, because they

have been told to shut up and get on with it for so long. Consequently, it is really difficult when they are interacting with a therapist. For example, when the therapist asks, 'How are you going with that exercise?' they reply, 'I think I'm going okay,' and they are not really reporting: 'Actually, it feels really weird. My muscles are beginning to shake and I felt like this for three or four days afterwards.' There is a multilayered problem with all this.

Ms Liethof: I just want to confirm what Blaise was saying. Something that I often hear Dr Steve De Graaff say is: 'If you ask a polio survivor to do five repetitions they will do 10.' The idea is that they want to be better and better at what they are doing. That can also be a problem.

Dr Tierney: I want to concentrate on a point in response to Mr Coulton's question about how different health professionals, while undertaking a therapy that is totally appropriate in their field, create problems in another area. They are not taking a holistic approach to a polio condition that they do not fully understand. I am sorry to talk about physiotherapists, Blaise, but when I was in my twenties I had my right knee operated on. It was not the polio leg; it was the one that was overcompensating. It had four operations and they finally threw it out and put in a totally new knee. That was only a few years ago.

CHAIR: How does that go?

Dr Tierney: Brilliantly.

Ms HALL: There is a little bit of self-interest in the chair's question.

Dr Tierney: I picked that up. I thoroughly recommend it. I said at the time, 'The other knee is not too good either. Why don't you do them both together?' but they would not do that, of course. Anyway, the physiotherapist correctly identified that above the knee the muscle was wasting. So I needed to build up that muscle. That is fine. But then he put weights on my foot and that accelerated the problem in the joint. That is why, even when people are doing the correct thing in terms of their discipline, they can create problems in other areas.

Ms Telford: I remembered the point. Rehabilitation is dominated by the medical model. What we are talking about are some of the social, emotional and psychological consequences. It is fair to say that there is a fair degree of mental stamina. We build up the muscles that we can and, mentally, many do that, but as far as I am aware there are no specific services provided or offered to people who are polio survivors, in terms of dealing with the transitions that they are going to have.

The second point I want to make is about access to information. Thirty per cent of our members do not have the internet. They do not have that because of their age. They do not have access to information, like the websites and so on that you have been referring to. It is really important that for that population there is information available in other ways or access is made available to them.

Mr IRONS: This goes back to diagnosis. John, you might be able to answer this because you went through the experience. The six-year average time to diagnose has been talked about. That means that for some it was around 12 years, and for you it was three weeks. Has there been any follow-up on the doctors who have become aware once they have made the diagnosis? Is it at the forefront of their mind for the next time? Do they go onto a type of register that says: 'This guy has diagnosed someone with PPS. They're capable of doing it again in the future'? Has the recognition of the original diagnosis helped them make an earlier diagnosis of someone later or do you think they are still as ignorant?

I cannot say whether or not the individual doctors have got better as a result of having done it, but I do know that support groups all around Australia collect names of doctors who you can actually refer people to because we get so sick of people ringing us up and saying, 'My doctor doesn't believe in postpolio.' So if you find somebody who is good then he becomes a very wanted commodity out there in the community.

Mr Dobson: There are extremes we have to deal with. Back in the early days of my current position, around 10 years ago, after a long battle I arranged a meeting with the chief executive officer of the Launceston General Hospital and asked her to consider putting on the questions that you are asked when you go in for surgery 'Have you had polio?' Well, did she tear strips off me. 'That is totally unrealistic, to expect us to do that.' Even though so many people who go in for surgery suffer because of the inappropriate treatment they receive, being over anaesthetised and all these sorts of things.

It was only a matter of months later that I secured a meeting with the state Chief Health Officer. After an hour of discussions with him, he said, 'The important thing for you polio survivors to remember is that you know more about your body and your condition than any damn doctor, including me.' He said, 'What you need to be is more assertive, and you have every right to refuse any treatment that you believe may be harmful to your condition.' This is what I have been encouraging our Tasmanian people to do: be more assertive. It is paying off. But, still, there are arrogant people in the health medical profession.

A classic example is with my two hip operations. After the first replacement I struck a very smart young lady, fresh out of uni, that insisted she come first thing after lunch to do the exercises you have to do when you are recovering from a hip replacement. I tried to explain to her as nicely as I could that that was a bad time for me because with the hospital routine of a morning you have doctors round, showers, bed-making and everything else, and first thing after lunch you are absolutely bushed. She branded me a difficult patient because I would not cooperate. Eleven months later I had the second one done. On this occasion I struck a gentleman who had been in private practice for some years, who had a bit more commonsense and experience on his shoulders. He looked at my records and said: 'You've worked with some of the best physios in the business. You know what you've got to do. I'll check on you every couple of days.' He was absolutely thrilled with the progress I made. These are the problems you are up against. You have some—very few—that understand our situation, and others that just make life a misery and do not accept that we cannot do the number of repetitions they want, and we have to do it when they want to.

Ms Telford: I would like to refer to two examples that people have sent in to me. One was regarding a person who had chemotherapy. She describes the lack of understanding of her condition while she was receiving that chemotherapy. Firstly, the chemotherapy had a much bigger effect on her than it might have had otherwise. The other was about the lack of understanding of the nursing staff. She was asked to immediately get up and transfer herself. She was not able to do that. That caused a lot of embarrassment and difficulty. This continued to go on. The other was from somebody who had had an epidural. His affected leg recovered much more slowly than his other leg, which also has consequences for the management of him as a patient.

The third example I wanted to refer to had a more catastrophic outcome, and a patient died last year. The nursing staff, or hospital staff generally—from what I have read of what his wife sent in to me—did not take up the offer of advice from where they could get advice, misdiagnosed and did not treat him correctly. The consequence was his death.

There need to be hospital protocols right across Australia. The Commonwealth and the state need to work together to develop protocols so that for anybody who has had polio and goes into hospital there are certain procedures and they get the information. I do not think it reasonable to expect that all nurses and doctors are going to receive that education, but if there were protocols and somebody identifies themselves—and I do think that most people will identify themselves if they have those kinds of difficulties—there should be protocols that are followed.

Dr Tierney: This is a nice segue to the point I wanted to make based on what Ms Telford just said. I recently had an operation. It had nothing to do with polio, but I was involved with an anaesthetist. The polio network has a guide on anaesthetics and surgery. It is a full guide, but I did not have it at the time. I had this little card that says, 'Medical alert. I have had polio and I now experience the late effects of polio.' I put that in at the hospital and asked if the anaesthetist could possibly look at this because it says, 'Polio survivors often require less general and more local anaesthetic and more pain relief than average.' Before he put me under, I said: 'Did you read that I've had polio and did you read that bit of information?' He said, 'What did it say?' So I told him. He said, 'It'll be all right.' He was very blase.

Ms HALL: Was it right?

Dr Tierney: I came out of it all right. I'm still here!

CHAIR: When there are certain guidelines you would think that those guidelines are being followed.

Ms HALL: Could you table, once again, the procedural paper on—

Dr Tierney: Yes, I am happy to do that.

CHAIR: It is moved by Jill Hall and seconded by Deputy Chair, Steve Irons, that we take that as evidence.

Dr Tierney: I will table the card as well, which you can photocopy.

Dr Peel: This is not my experience but a case report. The person who is suffering from post-polio syndrome writes that she underwent abdominal surgery, which resulted in 4½ weeks in an intensive care unit due to respiratory failure. She says that this occurred despite her alerting the anaesthetist and the nurse in charge of the increased sensitivity of polio survivors to anaesthetics and especially if the polio survivor had originally spent some time in an iron lung, which she had.

Ms Thomas: I have a case study that flows on from these. One of our members had an accident and came off his segway—he segued off his segway—and he says, 'The medical and paramedical professions are not always aware of what is good for us polios.' When the ambos arrived, one of the first things they did was give him a dose of morphine, despite him saying that it was a bad idea. He said he was concerned about the respiratory depressant

effects of it. Because of his physical deformity, his lung capacity is very low. He ended up in intensive care et cetera, with an endotracheal tube down his throat, attached to a ventilator. He was completely paralysed and could barely open his eyes. He said the paralysis was due to the effects of repeated doses of neuromuscular-blocking drugs. He said that polio is particularly sensitive to these drugs and they should use lower doses.

He reckoned that this totally slowed down his recovery from it.

He says the third issue is that all polios are adapted to their existing physical condition. His fall resulted in broken ribs and a haemothorax or bleeding in the lungs. He could not get them to take the tubes out because he said 'in his case, as a result of a pre-existing chest deformity and respiratory muscle weakness, his blood gases, particularly carbon dioxide, were already abnormal before the accident', and so they never came back to what the people in intensive care considered to be normal. If it were not a colleague who is a professor at Prince of Wales Hospital, who made a special trip down to Canberra, they would not have pulled the tube out. I hate to think what would have happened to him—and he is a doctor. Even though he was a doctor, he could not get them to take the tube out.

CHAIR: We have Mr Doran and Mr Dobson plus a question from Jill. We need to be mindful that this session is to be completed at midday before we move onto other topics like management and a whole range of other things. I am also aware that many people have to catch flights at some stage today, so we want to try and keep it on time.

Ms HALL: My questions can slip into another session.

Mr Doran: I would like to add that once again the literature is out there. There is a review paper by Lambert in 2005 that points out that there is an anaesthetic risk for people who have had polio—it is all there.

Mr Dobson: In my case, most of my surgery has been at the public hospital but some years ago I had to have an emergency operation that was not listed as compulsory. For my comfort, I decided to have it done in the private hospital. I left a note for the anaesthetist to check my records at the public hospital where they all are. When he came to see me, I asked him if he had had the chance to do that. He said, 'No. Do you really think it is necessary?' I said that I would feel a lot more confident as a polio survivor if he did. I saw him before I went into theatre. He pulled his mask down, so I recognised him and he said, 'Just as well you told me to go and check your records. I could quite easily have killed you.' That is how important it is that they recognise that there is a risk, and you should always make sure your records are available, if at all possible, and demand—as our health officer said—that they look at them.

CHAIR: They are things that we will discuss in management in the next topic.

Ms Telford: Even in cases where people demand to have their records taken into account, it does not necessarily happen. That is why I think there need to be protocols where they are required to, so the onus is off, particularly the family members who are in the distressing situation of trying to support their family member and not necessarily having the information or the knowledge.

CHAIR: Before I close this session, I would like to give the opportunity to Mr Booth and Mr Howard to add something. Mr Booth, we have got your statement, which has been tabled.

Mr Booth: I think I will pick up on a lot of the things later this afternoon.

CHAIR: That brings us to the end of topic No. 1, which was definition, prevalence and diagnosis of the late effects of polio and post-polio syndrome. We will reconvene at 1 pm.

Proceedings suspended from 11:59 to 12:55

CHAIR: We will now start our second session, in which we will discuss management and a range of other things. This session aims to consider how we manage the illness, including treatment techniques, therapies and aids that exist for people. Also to be discussed is how clinicians and allied health professionals are trained and educated about current treatment techniques and therapies. I know we touched a little on these issues earlier. We will have the same format as before, with five minutes for each person. We have a new witness, Dr Stephen de Graaff, who is here specifically for this session.

Dr de Graaff: Thank you for inviting me today. The issues around the management of the late effects of poliomyelitis and post-polio syndrome are quite complex. In the discussion this morning I understand that you were given some background into the process of the initial disease, with some restitution and recovery and then gradual decline for other reasons. The challenge in managing these patients is getting them involved in an adequate way to manage themselves, but that takes some expertise. There are some subtle differences between the late effects of poliomyelitis, which is more to do with muscles and joints, and post-polio syndrome, which is more to do with muscles and nerves. They can overlap and they can interfere with each other.

The biggest issue in management in the community is that most of us who go through medical school and allied health school are taught about acute illnesses. This is a chronic disease process, and the management is somewhat different. I am a rehabilitationist by trade, and this falls into my area of chronic illness management. The challenge is that the routine way to manage patients with musculoskeletal injuries or neural injuries is often one of reactivation—getting things going again. With this population we often have to deactivate the patient. We actually have to re-educate a group of individuals who have always done things in a dynamic way to try to be normal. They want to keep up with everyone else, given their physical losses from their polio. This adds to the extra stresses and strains on the neuromuscular and joint systems.

There is a real challenge in educating the treating population about the appropriate way to go. When I first started seeing polio patients—20 years ago, dare I say—we would not allow them to do any exercise. It was almost a rest process. We now know that some resisted exercise, some training, is appropriate for this group not necessarily for the limb that has been affected but for the total body. But that needs to be done in a careful, constructed way and there needs to be a lot of education of the polio survivors about how to manage themselves. If they are asked to do 10 repeats of an exercise, they should not do it in the old-fashioned way and do 20 repeats to show that they can do it. Part of the facade is: 'I can do this. I might have a physical disability, but I can do this for you.'

The other thing we have to keep in the back of our mind is this population, with time, have always been achievers. I can cite a number of people in the community who are very prominent and whom you would not know had polio. But then they stop achieving. Not only does that have a physical consequence, it has a psychological consequence. That is part of the disease process. Adjusting and adapting to your losses. Adjusting and adapting to how you can take control of things again. It actually needs a multifaceted approach. It should start at the doctor, who needs to have an understanding that the people with polio do not still have an acute infection, but actually have a degenerative process that is occurring, and his understanding of relying on a team of physiotherapists, maybe occupational therapists, orthotists and psychologists to be able to use those resources to assist the person with polio.

The difficulty with this population is they often start giving their symptoms, they then deny that those symptoms are occurring, because that gets in the way of achieving, and then a catastrophe occurs and they are behind the eight ball. The secret to managing these guys would be: we are starting to get in a bit of trouble, what is the cause? Let us have a look this. Let us put some strategies in place to help you manage in the long term. Do not rely on the medical system—have it as a backup. That is a huge conceptual change for a lot of practitioners, but it is not a difficult conceptual change. Rehabilitation is a big industry now, and we have an understanding of this. We spend a lot of time with our trainees working through these processes. The information is out there within some of the medical field, but also within the literature. There is literature showing management. The Mayo Clinic, for example, puts out a lot of literature on post-polio management. Who is going to conduct the education and teaching? That needs to start in schools. We need to get into the schools, encourage part of chronic illness management, which has not been occurring in this area. We do it for diabetes. We do it for MS. We can get this involved as well and use those strategies to help.

There is a question here on consultation in terms of the manufacture of aids to assist people. That generally starts with someone with knowledge about the late effects of polio. Unfortunately, patients with polio will go to their general practitioner. He says, 'We will send you to the physio,' and sends them to a routine physio. We also have to educate GPs that there are orthotists who play a very important role.

My final comment would be that you need to have a strategic set up, where this information is held within each state. I was working out the figures: probably between 0.6 to 0.8 per cent of the population are polio survivors, with 20-plus million people in our community. That is 150,000-plus people in the community who are potentially polio survivors who may well be getting into difficulty.

CHAIR: Thank you very much, Dr de Graaff. We will move down to Mr Dobson. You do not have to make a statement.

Mr Dobson: No, I will pass.

CHAIR: Mr Booth?

Mr Booth: Thank you for that. I did say I was going to leave it until the end, but I thought I would make a couple of very brief comments. Just picking up on some of the previous speakers' points and also picking up on some of the points that have been made earlier this morning. It was just really to emphasise this notion that primary health care as a whole is going through a period of quite profound change at the moment, in terms of the health system being driven by the increasing chronic conditions, by an ageing population and by differential costs

of health care. We are seeing a move from an acute hospital based health system to one where we really need to try and reorientate things towards a much more preventive primary health care—home based care—of health and treating people.

One of the key things within that and that was mentioned this morning was the importance of multidisciplinary care approaches to treating this population. I think that is a very valid point. Certainly, one of the things that we are trying to do at a Commonwealth level is encourage a move towards multidisciplinary care, really away from a traditional, almost single handed GP model of care, through to one which encourages multidisciplinary team based approaches to treating people in a more holistic way and formally trying to connect GPs with allied health, with community based workers et cetera. One way of doing that is through the GP super clinic scheme, but there are many other models throughout the country that are trying to do this as well.

Another interesting point that has come up is around the importance of care coordination for people with chronic conditions as well. That is another thing that we see as being very important to ensure that people with chronic conditions—people who need this help—can access some kind of care coordination services that can almost guide them through the system. The final point I would make, which I have written down and which Dr de Graaff mentioned, is the self-management area. Again, this is quite a significant change for the health sector as a whole. It is almost a cultural change that we are working through. So that is just a bit of a backdrop to some of the more detailed discussion here.

CHAIR: Thank you very much, Mr Booth.

Mr Doran: What I am going to do is segue from that to talking about Polio Services Victoria because it is the only polio-specific service in Australia that provides any kind of service to polio survivors. Based on who is registered with us, we know there are about 1,300 people in Victoria. I suspect the number is much higher. Those are just the people who choose to come and see us. Lots of other people go and see Dr de Graaff and other clinicians. The thing with that is we have four clinicians, two of whom are part-time and two of whom are full-time. But we do take this multidisciplinary and in some cases almost transdisciplinary approach and I will make the differentiation by saying that I would trust my orthotist colleague to make calls on what would normally be deemed physio-type problems, and likewise the occupational therapist and I work very closely on wheelchair and seating assessments—necessarily so, because there is no other way of doing it. All our clinics, which are for the medical one, occur about every couple of weeks and they do six regional clinics as well. Usually it will have the doctor, the orthotist and the physio involved—there is a necessity for any chronic disease group to have that kind of multidisciplinary approach. Certainly the best way we can make it work is by doing it that way. But what we then have to do is refer them on to the local service providers and therefore our role becomes a different one. Probably 90 per cent of our treatment is education anyway, as Dr de Graaff touched upon. I also think we have to educate the wider community—educate the clinicians—and we do that in a variety of ways. You have seen some of our literature on things like anaesthesia and surgery. We have a whole raft of those.

CHAIR: We spoke earlier about the pack you sent out.

Mr Doran: Yes. We send out all sorts of things to people. Also, at the end of every letter that I do as a referral letter is, 'Contact us. If you have any questions or any confusion, or even if you just want to talk about this rather prescriptive referral that I might have done for you, contact me,' because that is what we are there to do.

CHAIR: Thank you very much.

Dr Tierney: The sorts of solutions in the management of this condition can be very low-expense solutions. Not only is the way forward not all that costly but, if the condition is managed correctly, it can actually take a lot of hidden costs out of the system that currently exist because you have people who are taking too many pharmaceutical products. You have people, as we heard in the case of the anaesthetist, who have to have a whole lot of expensive interventions following it, because they were not given the right anaesthetic to start with. You have people who go to the gym overexercising and then creating a huge number of extra costs, particularly if they end up in a wheelchair and then there are all the costs that proceed from that. None of that is recorded in the financial systems of the health thinking. That is not being tracked at all. But you can tell by the way people are mismanaging the condition how much extra cost there must be in the system. What we need here is a system—very much in line with what is being said about primary health care—where people are self-managing the conditions. But to do that they need a few tools and to a large extent a lot of the tools are there on the internet, but people do not know they are there.

So there needs to be a higher level of awareness developed and community education programs. What is particularly important is doctor and allied health professional in-service training in the diagnosis and proper management of this condition.

The sorts of things that people have to do to manage this condition are not really rocket science. It is all pretty straightforward and sensible, but if you do not do it properly you are going to create horrific medical problems for yourself further down the track. In my case, when I started to self-manage my condition in 1994, not a lot was known about this. A lot of doctors would say to me, 'You are just getting older.' There was not much out there to tell you that that was different. It only came home to the medical profession, in my case, when they looked at an MRI. But of course you had to have an MRI first. I cannot recall how I sourced that, but I think I convinced the GP to refer me to the spinal specialist, who did the MRI. It was just staring at him. What he saw was this: spinal stenosis, which is a narrowing of the spinal column, from L1 to L5; spinal scoliosis, which is curvature of the spine; arthritis through a whole range of the backbone; collapsing, compressed and protruded discs; and three major spurs growing into the spinal canal—you normally have about 80 per cent wriggle room in your spinal column and it was down to about 10 per cent. It was quite obvious. Of course, being a surgeon, he had a surgical solution: 'What we do is we operate and we take these spurs out.' But he was a spinal professor and was a bit broader than your average surgeon. He said, 'Well, let's try to manage this.' He said to me a few years ago, 'Fourteen years ago I could have sold you an operation.' He put it that way—I could have sold you an operation.' I thought, 'Well, let's try to manage this and avoid the operation.' We have blown the time out, because he initially said 10 years. That was 1994, which then took us up to 2004, and he did not operate then. He looked at me two years ago and said, 'Maybe another two years.' That is now. I know I do not need an operation. And I would say, maybe another two years. What happens is that you have moved on from it being a 10-year time frame to a 20-year time frame.

CHAIR: That is because of good management though.

Dr Tierney: Yes, it is. The magic of what happens with medical procedures of course is that over 20 years there has been a considerable improvement in that procedure. Operating right up against the spinal cord and taking out those spurs can be quite dangerous, but there is now some new procedure where they do not actually take the spurs out; they do something else to increase the wriggle room. So it is less dangerous. We have not quite got to that particular point yet.

What I have found most useful is an osteopath. The osteopath looked at the MRI and said, 'Boy, you're a mess.' He said that if someone presented with one disc looking like mine they were in huge trouble—and I had five. But we are still managing that situation. As I said before, it is not rocket science. Every second day I go to the heated pool. I do hydrotherapy for 45 minutes—a whole series of exercises and a bit of swimming. The other day I walked the dog and did a bit of work on my stationary exercise bike. And that, together with working with an osteopath every two weeks, manages my condition. There is not a lot to it, really. One of the things the osteopath has done has been to reduce a problem that was there over 10 years ago, where the nerves were pinching in the back and causing all these spider feelings down the right leg. That has gone. That has gone because of the work of the osteopath, who works with bone and muscle to get the whole thing done. That is the management of the condition.

If we had everything in place, particularly if we had proper education programs for doctors, parahealth professionals and people who have this condition, I really believe that you would have a situation where people could manage this.

They could stay in the workforce longer. If they do that, they pay more taxes. As I mentioned earlier, I retired at 65. I finished parliament at age 59. I could have gone then, but I worked for another six years, paid taxes for another six years and, because I managed the condition properly, I have taken a whole lot of costs off the health system. That is just one person. Multiply that across the cohort and the plus money and the minus money changes are just massive. That is why I believe the parliament and the government should really look at this issue very seriously and, in line with what the government is now proposing, with a bigger emphasis on primary health care, I really think our time has come to put in place proper strategies to manage this condition.

Ms Liethof: I would like to talk a little bit about what Polio Australia has been working on over the last three years regarding the management of polio in the light of the fact you already heard that a few of us went over to Warm Springs, in the US, and we participated in a health and wellness retreat. I was able to get one of those up and running in New South Wales in 2010, last year in Victoria and this year we have one in Queensland. We are hoping to move it all over the country. We believe that this has proven to be very effective for the participants who have been able to attend. We limit it to up to 70 participants and their respective partners and/or carers, because people have actually brought along a spouse—often it is a daughter—to these activities. Because it is over a three-day period we focus on the body on Friday, the mind stuff on Saturday and the spirit on Sunday, which seems to be appropriate.

In the feedback from that we found that people have really benefited from having concentrated time amongst themselves, also with a range of allied health professionals and a whole range of other people who have taught things like seated yoga and that sort of thing. It has also helped to have their partners with them as well because, in a lot of instances, what we saw in the presentation that Gillian gave earlier on was that partners and carers of people who are experiencing late effects of polio are largely unaware of what is going on for that polio survivor themselves. That person has generally been a very high achiever, highly organised and has been the person who has everything happening—dinner on the table at seven or whatever they have needed to do to run a tight ship. All of a sudden, they are not able to do that anymore.

In a lot of instances there is a lack of understanding amongst their nearest and dearest because the polio survivor has trained these family members very well in the fact that they are superpeople. Now they are not superpeople—they are still superpeople, but their physical capacity has diminished. So having everyone involved in this, if you like, immersion therapy, seems to have proven to be a very effective model for self-management, although it is limited. The idea that people can get everything in one fell swoop over a period of three days seems to have been quite an effective model. But, as somebody said at one point, we are punching way above our weight. As I said, I am the only paid person, through philanthropic funds, over a three-year period. I am in my second year. I am the only one doing any of this.

Another thing we like to do through these activities is to educate the local allied health professionals and others about what is going on for polio survivors there. I approach local physiotherapists and they go: 'I don't know anything about polio and the late effects of polio.' I say: 'That's fine, because we know a lot, so we can provide you with this information. Please feel free to call Blaise.' And they do. We are educating people in those local communities.

We are fighting like mad to get funding to put these things on, and the benefits are coming out. The people are leaving these retreats, going back to their own various health professionals, going back to their support groups and their communities and they are spreading that type of management. They are also talking amongst themselves. If there is one thing that polio survivors are very good at, it is sharing information amongst themselves. What they are learning from each other cannot be denied either. So it is a model.

Ms Thomas: The rest of Australia is pretty envious of Victoria with Polio Services Victoria. What has been done in the other states is that peer support groups are the ones who have been trying to provide the information to polio survivors—trying to find the polio survivors and then give them techniques to manage their condition. The way we have been doing that is by holding seminars, conferences and whatever, all done on a volunteer basis. In Western Australia, there is actually a 'late effects of disability' clinic which sees polio survivors. It also sees cerebral palsy and stroke survivors, but polio survivors, I think, make up the majority of people that it sees.

Polio Australia came into being because we could see that the state networks were not going to be able to keep going forever, because of the fact that the majority of them are volunteer based or they are self-funded if they have got employees. The state networks cannot keep going. It is unsustainable. I do not know how they have been going for the 20-odd years that they have been going, really. I have been involved with the Post-Polio Network of New South Wales since 1988 and sometimes wonder how I keep going.

Polio Australia came into being to try and get funding to get services in place, and consistent services across Australia, so that people could learn about management of their condition. One of the things that Polio Australia has put in funding for is prevention, early intervention and management of the late effects of polio, which would have three streams, one of which is what Mary-ann just described, our self-management residentials.

Another one is community education, which is really needed. That would involve having a community development worker in each state to go out there and talk to people and help the networks to try and keep them going a bit longer, because they are needed out there and they are providing such a wonderful service to their fellow polio survivors. But they cannot keep doing it on the smell of an oily rag.

The other thing is to come up with polio fact sheets and videos for consumers. Polio Australia's remit is to produce nationally consistent information, and that is a thing that we think is really important—to provide these fact sheets and videos for polio survivors.

Ms Telford: The first point I want to pick up on is Mark's point about—I do not know if he used the term—the whole-person approach, which is what I think is needed. We are very fortunate in Victoria to have Polio Services Victoria, but it is a consultation model and it leaves huge gaps. The assessments are made by the physio, the orthotist and the doctor. It is not necessarily easy for anybody to have an assessment and be told the confronting news that they need to cut back to 60 per cent or something like that of what they are normally doing.

I have had lots of feedback from the members about what their experience was like—and my own personal experience too.

Polio is not discriminatory in who it affects and, while there is a point that there is a sense of trying to achieve, anybody who is confronted with obstacles in their life is going to try to push past those obstacles. The point I want to make is that we are a diverse group. The people that have come along are engineers, musicians, lab assistants, social workers, even politicians. The service has to take that into account and so I would like to see a holistic model.

The other point I want to make in terms of management is that bracing is crucial for a large proportion of us. Over the break the point was made to me that there are some people who have spent over \$30,000 on equipment. Getting bracing requires very careful assessment and, even with the best assessment, sometimes it is wrong for you—it does not work and you have to get something else. When I got the top-of-the-range stance control the technology was really sophisticated. It cannot be made at PSV—is that still correct?

Mr Doran: It is correct at this point in time, yes.

Ms Telford: It was not appropriate for me and I now have this other model. That cost me \$4,000 on top of the \$2,200 that I received in funding. I then had to wait another year plus to get the funding for the next one. There are many examples like that of people waiting.

The other thing is that there is a crisis in the orthotics field. I think PSV is unable to provide orthotics partly because of a lack of technicians—I will get corrected if I am wrong—and there is also a lack of trained orthotists in the private sector. A number of us see Darren Pereira, who is the best trained orthotist. There were others who were trained at various other services, but they are retiring and people are not picking it up. I am aware that at PSV—I did not hear this from anybody at this table—they will not pay above award wages and so it is very difficult to attract—

Ms HALL: For clarification, you said 'in the private sector'. What about the public sector? I have heard about the lengthy waiting times for people to see orthotists.

Mr Doran: Twelve months plus.

Ms HALL: So it is equally as bad, whether it is the public or private sector. Is that correct?

Ms Telford: If you go to a private orthotist and you are going to apply for funding through SWEP, you still have to wait—sometimes it can be for two years. I know people who are still waiting at two years plus. In the private system, once you get your funding they will be able to make the orthotic for you, whereas in the public system they often do not have the technical expertise or the staff to make it. In one case, somebody is waiting for something to be sent to America.

CHAIR: Just before I go on to Dr Peel, I think there was something that Mr Doran wanted to clarify.

Mr Doran: I wanted to clarify that, in the Victorian model for funding, the \$2,200 that Liz Telford has talked about—yes, there are wait lists for that. It is nine to 12 months before that funding will come through for non-urgent items that people apply for. There is only one place in the whole of Australia that trains orthotists and that is La Trobe University. I do not know what their intake is, but their output is probably 60 orthotists a year, for whom there are not enough jobs, if I understand correctly. They sometimes have to move abroad, to New Zealand and so on, to get jobs.

The making of a knee-ankle-foot orthosis, the complex piece of kit that Ms Telford was talking about, usually requires a more senior orthotist.

Ms Telford: I want to go back to supporting the model of the retreat. That model is an excellent model. I was also at Warm Springs and have been at each of the retreats and have participated in various ways. However, the retreat is self-funded, so it is a very expensive thing for people to do and not everybody is able to access that. The other point I want to make is that there are a number of people from CALD communities who are under 40—and here we have people from Asia and India—and we have to look at ways to connect with those people. Their needs are different. I really think that anyone under 40 is not going to pick up on a service that is focusing on what might happen to you when you are 50 or something. There needs to be some way to connect with that community, and funds need to go into that.

There is one other thing about assistive devices and braces. Under the chronic illness program where you get five sessions—I have forgotten the actual name of that Medicare program—orthotics is not listed as one of them. So I could get my caliper or brace and if it breaks I will have to fund the repair. To go to the private orthotist costs \$120. If it is in the warranty period it will be covered but after that we have to fund it. I know of people who have not been able to afford that so have not had their braces repaired.

Dr Peel: My personal experience leads me to focus on the need for raising awareness of the extent of the problem of falls in polio survivors and the need for more appropriate management programs for their prevention. Data from the general population shows that about 30 per cent of people over the age of 65 years fall once a year, 10 per cent fall more than once, and approximately 10 to 15 per cent of those falls result in serious injury. These injuries are the single biggest reason for hospital admissions in this age group. The cost to the health system is estimated to be about \$7,000 per incident.

With post-polio syndrome the reported fall rates are significantly higher—at least double that. A further complication, as reported at the Warm Springs conference, is that the hip associated with the leg with the polio affected muscles is commonly affected by osteoporosis. That means the risk of fracture is also greater for the population post polio. There is published evidence supporting this high rate of falling. In the Netherlands, 74 per cent of 304 polio survivors reported at least one fall in the past year and 60 per cent reported two or more falls. In the United States, 64 per cent of 233 polio survivors reported that they had fallen in the previous year and 61 per cent had falls for which they received medical attention, and that included 35 per cent who had at least one fracture. In Ireland, 64 per cent of 50 post-polio patients had experienced falls—but that was in the previous six months—and 19 of those 50 had reported a fracture in the past five years.

Based on the assessments of their bone mineral densities, 28 of those 50 patients were diagnosed with osteoporosis and a further 20 were diagnosed with osteopenia, where the bone mineral density is not quite so low. That amounts to 48 out of 50, and only eight of them were actually receiving some therapy for their low bone mineral density. So not only is there a much higher risk of falling in the post-polio population; the incidence of osteoporosis and fractures is also higher.

For the general population, it is well established that exercise in older persons can prevent falls and reduce the rates of falls significantly. A comprehensive Australian review and analysis from the Prince of Wales Hospital and Sydney university showed that as many as 44 randomised control trials had established the fact that exercise can prevent falls in older people, especially exercise that challenges balance. At the international Warm Springs conference I attended a lecture at which it was pointed out that maintaining posture and balance in the post-polio population very much depends on the conditioning and strengthening of core muscles—the trunk muscles—and the muscles up through the neck that are involved in posture. It is recommended that improving the function of those muscles will improve balance and help prevent falls. Specific balancing exercises, including standing on one leg while holding on to some kind of support and moving the other leg, can also be done in polio survivors. They are even easier in water.

I crave your indulgence; I want to mention my experience with falls. Several years ago I had fallen three times in a three-week period, so I approached the Neurological Disorders in Ageing and Balance Clinic, which is a physiotherapy clinic at the University of Queensland that is open to the public. I specifically requested exercises to improve my balance. I was prescribed nothing more than eye exercises—nothing more. I know vision plays a role in balance, but I was quite convinced that doing eye exercises would be of no value to me. More recently, I discovered that I too have low bone mineral density in both hips but significantly lower in my left hip, associated with my polio affected leg. Further, at the testing clinic, I had to argue for both hips to be tested because the routine is to test the right hip only.

Published reports support the implementation of exercise programs to strengthen the core muscles and to challenge balance. Of course those exercises have to be tailored to the capabilities of the individual with post-polio syndrome or the late effects of polio, but so do all exercise programs. But they should be implemented to help prevent falls.

It is a very complex issue and, of course, there are other aspects. You must avoid environmental hazards and risky behaviours. Also, there is a role for orthotics. With foot drop you can trip over your own foot and so orthotics that counteract the foot drop help prevent falls, as do orthotics that stabilise weak knees that might otherwise just fail.

A survey in Queensland in 2008 showed that 30 per cent of polio survivors live alone in units or houses. Therein lies another potential danger. Polio survivors can fall and sometimes they cannot get up from that fall, even in the absence of a fracture. It should be recommended to them that, for those situations, they wear some personal alarm and also install a key box on the outside of their house—a safe box so called—so that when help arrives you can ensure that people can get into the house. Overall, I feel that healthcare personnel need to better appreciate the high rate of falls and osteoporosis in polio survivors with LEOP/PPS and to implement evidence based management programs to deal with this particular issue.

CHAIR: Thank you, Dr Peel. We will now go to questions from the committee.

Mr COULTON: I have got a couple. First, I will make a comment. I think an ideal place for a health retreat would be in the north-west of my electorate, where we have healing waters of the underground springs in Moree or Lightning Ridge, or one of those exclusive places.

Mr IRONS: Are you including yourself?

Mr COULTON: I could organise something. In relation to the people I represent, are people losing mobility through having to hand their drivers licence in? Are the sorts of effects that people are having effecting their ability to drive? That is a short one. The other one is, if you had the health minister's chequebook for a day and you were going to organise a program to bring this to the forefront—from what I can see, you are battling on two fronts. One is the understanding within the medical profession, but a greater one is probably that there would be a lot of people who do not know that they have been exposed to polio when they were younger. A lot of people are feeling around in the dark. There is an advertisement encouraging people who are Indigenous to identify themselves to their GP. I do not know whether you seen it; it is all over Australia. Is that the sort of thing you are looking at to try and build this up to a higher level?

Ms Liethof: On your last point, I think that is an excellent thing. I think that we definitely need some kind of Australia-wide media campaign. One of the other things that I am doing at the moment is looking at putting in—just because it is all we can do—a submission to SBS, because once a year they put out a submission for a one-year partnership. We would have to make our own advertisement, but at least that would appear on SBS TV, which might go some way towards notifying the CALD community, which would be excellent. But that is all we can do with this. If we had the health department chequebook, obviously what we would be looking at would be a concerted campaign not only to sort of say, 'Identify yourself as a polio survivor' per se, but, perhaps 'Sign up to the Australian Polio Register,' would be a definite first. We could definitely get the message out there a lot more by just sort of saying, 'Do you know?', even to brothers and sisters of polio survivors. Often, if someone in your family has had polio and is a sibling, you probably had polio yourself. Definitely, we would love to see a national campaign out there.

Mr COULTON: If we flush all these extra people out, can we look after them?

Ms HALL: We will anyhow, won't we?

Mr COULTON: Yes.

Ms HALL: Only you will know what you are doing if you know what the cause is.

Dr de Graaff: But can you look after them effectively, is probably the question.

Ms Liethof: If we had the package of information that we would like to produce, then at least we can advise and inform people about that. As other people have identified in their case studies, just knowing that there is something called the late effects of polio or post-polio syndrome is something that they can actually start working with rather than imagnitis.

CHAIR: In the previous session we spoke about a lot of doctors, even today, not accepting the late onset of polio. How would you combat that?

Is it a big divide in the medical profession? We touched on it earlier. Is there someone here who might be able to speak to that?

Dr de Graaff: The difficulty is that the symptoms of post polio syndrome and late effects of polio are often similar to other similar less stringent diagnoses—rheumatologic diagnoses, like fibromyalgia and chronic fatigue syndrome. Often a polio survivor will get lumped into that group. When you treat this population, you find they are a different population; they are still trying to do things, whereas the others are tending to pull away; that relates to the comment I made before about needing to deactivate rather than reactivate. So, as a general rule in a busy general practice and a medical model, a doctor might say: 'Sounds like fibromyalgia. Can't find anything.'

The difficulty is that there is no actually classic clear diagnosis of post polio syndrome or late effects of polio. It is a constellation of symptoms and signs. You can diagnose that someone has had polio with electrophysiological studies, but all that tells you is that they have had polio. That is a starting point, in terms of trying to manage somebody. As a practitioner, the best way of diagnosing is through the clinical history, and there are usually subtle things that you look for there. When you do that all the time, it is not so difficult; when you are in a rushed five-minute consultation, you are not taking all that information in. So that is where it comes back to information out there being available.

Let me say in due deference to John Tierney, I do not think it was the osteopath or the surgeon who has made the difference in the end; it is John who has made the difference. That is what you get with this population. This is an incredibly industrious, intelligent population who have fought the odds and succeeded. That is how they

manage. If they can get a construct that helps them manage—that means information out there—they can take that away and use that to their advantage. But we have to get it to them earlier than what we are.

CHAIR: What I was trying to ask, you have partially answered: is there a clear divide in the medical profession, as there is in many other things, or is it just something they are not aware of and, therefore, they do not diagnose it and they go on with other things?

Dr de Graaff: That is a good question. Firstly, medicine works through scepticism. If you do not have proof that something is there, you will not diagnose it. So there is a divide.

There was mention of the holistic approach. You have to move out of the medical model; you have to look at the functional model, and how the person is coping. You have to look at the way they work through their day. You have to sit back and look at them in a different way to the normal medical model. A lot of medical practitioners are not trained in that. Surgeons—no disrespect—are focused on what they have to do. Occasionally you will get a good surgeon who thinks beyond that model and they are often leaders in their field. So there is a divide in terms of the way people approach it, not necessarily—

CHAIR: Not that it does not exist or that they are not interested in talking about it.

Dr de Graaff: Yes.

Mr Doran: I want to segue from that into trying to answer a couple of questions. Most allied health and medical practitioners have all the skills they need. It is about how you apply them, and how you start to reframe your way of thinking. I suppose that is where we are at. We have to find a successful way of doing that. We have to come up with some fantastic ideas about how we could do that, and without it costing quite so much.

To come back to your question about whether or not people are having their licences taken away, there is a complicated system. In a way, the onus is on you to report whether you are having problems, and, when you report having problems, they take your licence away, so people tend not to do it. What tends to happen is that we will spot things and say, 'You have two leg braces, and your legs are getting weaker; how are you going with your driving?' 'Oh, well, you know, it's not crash-hot anymore. I probably only go around the corner.' A forgotten group of clinicians who are really important for this group are the occupational therapists, because they are the people who really look at everyday function.

When Dr de Graaff talks about stepping back and looking at things from a functional point of view, it is an extremely important profession to involve with this group of people, because they are going to look at anything—driving skills, access in and out of their own building, how to conserve their energy and yet still do what they want to do. There is wheelchair and seating, beds and pressure care. There are all sorts of things that they get involved in as well. It just highlights the fact that you should not take a purely biomedical approach with this group of people. It is a difficult one because there is a certain self-reporting element with the driving thing.

Mr COULTON: The point I was making was that if you live in a regional area and you are a couple of hundred kilometres from a reasonably sized town, then lack of mobility has a whole new meaning.

Mr Doran: You need to drive, yes.

Ms Telford: I want to pick up on the osteopaths. John Tierney was talking about the assistance he got from the osteopath. We have had a lot of members also reporting about the support they get from the osteopath, and I wonder whether there could be something in terms of looking at those education models involving the Osteopathic Association. That is one point.

In terms of the point about identifying the extent of the problem in the population, I would be concerned if the lack of resources to care for the people with this problem would prevent us from trying to identify the extent of the problem, because I think that the statistics can be skewed. We will not look for them because we do not have the resources, and that is what I think is happening at the moment. The other thing is about the statistics. I do not think there are any non-urgent orthotics requirements. Whenever you need an orthotic you need it now. I have a number of cases of people who have written in and talked about how their pain has increased and how their mobility has decreased, and falls have occurred while they are on the waiting list.

Dr de Graaff: I have two quick points. The first point is that often practitioners, including doctors, are threatened by patients who know more about what is happening to them than they do. That is a big issue in management. That gets that divide in place as well. The second thing is about orthotics. Liz commented about the orthotic not being right for her and having to go to another orthotic. The best orthotists are those who have the experience to understand and listen to polio survivors, because they know what they need for their mobility. We tweak the edges, but they generally know what they need for their mobility. The difficulty with a lot of the orthotists is that they come out of acute settings and are used to doing straightforward things. You do not have an

acute situation. You often have an acute situation on a chronic situation. So there have been tools of management in place which need a bit of tweaking to move on. It needs that level of expertise.

Mr Doran: I will add to that. Absolutely, in terms of orthotic provision, I could not agree with Liz Telford more. It needs to be much more urgent than it actually is. But I am talking about the reality of how it is delivered. There is a deal of difference between what is clinically most appropriate in an orthosis and what is functionally most appropriate in an orthosis. That is where the art rather than the science of making an orthosis comes in.

Mr Dobson: Getting back to Mark's first question about the driving, the fatigue aspect of delayed effects of polio is what affects me the most. There is no way in the world that I would consider driving in my present state, and I will not consider driving. I would have to have two good nights sleep before I would consider driving. I try to do most of my driving in the morning. Because I live alone, I am missing out on an awful lot of social life because I am not safe to drive. I think I am reasonably sensible in knowing when I can drive and when I cannot, but family members, extended family and social groups like Rural Youth, which I was involved in years ago, look at me and reckon I am all right. They say, 'Why don't you come and join in the reunion, you unsociable old coot?' and things like that. They do not understand. But I know that the white posts get awfully close to my car if I try to drive when I am not supposed to. That is altering my life so that within the next 12 months I am going to have to go and live in a unit in town.

CHAIR: So it is not just about the actual driving; it is the perception that other people have of you as well. They think, 'Why don't you just come along?' but the reality is—

Mr Dobson: Yes. They do not understand that—

CHAIR: there are a lot of steps that have to be taken before you actually make those arrangements.

Mr Dobson: Yes. The fatigue is just getting that way that it is affecting me and affecting my work as secretary of the Tasmanian network. I am finding it much harder to do what I have to do, which is why I have resigned, but I am still acting because no-one else has put their hand up to do the job. I am going to get to the stage where I am just going to have to disconnect the phone and not bother looking at the computer.

Dr Peel: On orthotics, it took me 10 months to obtain a new calliper and medical grade shoes when I first moved to Queensland. In those 10 months I was experiencing increasing pain. But, whenever I complained, nothing was done. I have another friend in Queensland with post polio, and she has had to undertake the business of getting new callipers and medical grade shoes three times in the last 17 years. Each time it has taken her longer than one year to get them. We both worked through the Medical Aids Subsidy Scheme, which is a state scheme. The real problem with it is the timeliness.

Ms HALL: Thank you very much. First I would like to make a comment on the driving issue in relation to an occupational therapist doing the assessments. How often do your various groups utilise hand aids for driving and the modifications to cars that can extend people's time driving? Maybe you would like to touch on that.

Mr Doran: Yes, that is what we refer people to do in a case coordination fashion. As Mark was talking about, part of the job is to find the person the appropriate occupational therapy service that will be able to facilitate hand controls and whatever adaptations need to be made.

Ms HALL: And funding availability?

Mr Doran: It is there, I believe. But the major problem with most funds available through state governments is that they go only to a certain level.

Ms HALL: Yes, and it also sometimes links to work.

Mr Doran: And the availability of people who have the skill to do it.

Ms Thomas: I just want to make a couple of points—I didn't get my hand in earlier—about management of the late effects. It is not only the polio survivors but the carers and the families—the whole range of people involved—who need to be supported. If you do not manage your post polio properly, you put excess strain on your family relationships and on the people who are helping you. We are aging, and our carers are aging as well. They might damage themselves because they have been helping you when they should not have been because you have not got other services in place. It goes into a spiral. I had a problem where my carer broke his hip, and I ended up in a nursing home—which was fun!—because that was the only option available for me at that time.

The other point I wanted to make was just to say that the New South Wales network, under its previous name, Post-Polio Network NSW, did some extensive research amongst its 1,000-odd members. About 60 per cent of them responded to the survey we sent out. That survey was on the whole impact of the late effects of polio—what they are going through, what management there is, what problems they have with doctors, what expenses they

have et cetera. A whole range of issues were covered in that research. There is a copy in the Parliamentary Library and it was sent off to quite a number of politicians as well. That is a resource for the committee.

CHAIR: Thank you.

Ms Telford: On the costs of the modifications, I have an example here of somebody who had to have the doorways in their single-level house widened. There were a number of home modifications—thousands of dollars worth. They had got a new car that would take a scooter. That is not talking about what the car is in terms of hand modifications; it is about their being able to transport the electric wheelchair or electric scooter. Then you take all of those modifications on the house. It depends on what the house is. It might be an older house and you have to get rid of steps. I do not know what funds are available for that. That is another aspect: the lack of information. We need to be informed. I know that the person in this case funded it themselves and I know a number of other people who have had to do that themselves, so that is another aspect. If there is funding there, as somebody said, we do not know about it.

CHAIR: For whatever it is worth, I think the NDIS, when it does come into effect, will look at a lot of these things. But that does not solve the problem for you. So it is over the next few years that it comes in.

Ms Telford: But it is not for all those groups. It is if you are under 65, I believe.

Ms Liethof: A lot of people are actually having to fund everything because of the timeliness issue. You cannot get retrospective funding so you are made to wait and wait and wait—and people cannot wait so they pay for it themselves. There is no recompense.

CHAIR: What is the average time? I suppose different equipment has different waiting times. What is a short average time and a long average time that you wait for something in particular? Can someone give us some specifics?

Mr Doran: If somebody were to get funding in Victoria at this point in time the quickest they would get it would probably be within three months. So that is in terms of the funding and then obviously there is the manufacturing time. Is there a straightforward orthosis? I do not know. But if there were a relatively straightforward orthosis for an experienced clinician, you would say four months.

Ms Thomas: On the waiting time for an orthotic, the person who actually runs our NSW office is a polio survivor. He has been waiting on an orthotic. I think the funding was approved 12 months ago. He had his first fitting last week. So 12 months ago the funding was approved and it has taken 12 months since the funding was approved to actually get the first fitting.

Ms Liethof: One of the other things that I have heard with regard to the funding is that it really depends on what time of year you are applying for it. There is a new influx of funding at the beginning of the financial year and there is a flurry of activity around that time and then by the time September comes there is none left.

Ms HALL: I will touch on funding and then I will go to my question. There are lots of different sources of funding. There is Commonwealth funding and there is state funding. In a past life I used to link in and have a little bit to do with it. I think the one thing that is constant across all areas is the fact that obviously funding runs out. It is very difficult to find out information about the funding that is available. It is difficult for people who are actually working in the field. It is an unsolvable mystery for the people who actually need to utilise it for some form of home modification. Maybe a recommendation could be that we need to put in some central place information on the type of funding that is available, on the pools of money that we can link into. That is something that I think the department is in a good position to take up. The other thing that I wanted to bring up is something that came up in the previous session when we were talking about treatments, anaesthetics and medication and about when a person is hospitalised, given the lack of information.

It could also link into the need, in all health surveys, for there to be one question—on the admission form or when you move from one medical practice to another—which would ask, 'Have you had polio?—yes or no,' in the same way that we ask, 'Do you have epileptic fits?—yes or no,' or 'Have you got diabetes?—yes or no.' Along with that question, within the 'medical facility'—I use that term to generalise it—there would be a set protocol for dealing with medications: 'Medications—yes; medications—no.' My thought was: do you think we could come out with a recommendation on that from today?

Mr Dobson: Unfortunately, Jill, there are a lot of medications that I am on that I know do not help my polio situation. This is a problem for those of us with several conditions. I do not know what the answer to that is.

Ms HALL: Some things are life threatening, we heard earlier.

Mr Dobson: Yes, that is right.

Dr de Graaff: My comment in terms of medications is two-fold. You could certainly use polio as one of the neurological screens, like stroke and MS.

Ms HALL: Absolutely.

Dr de Graaff: It is not a difficult thing to add to a routine form. The second comment is that medication should be prescribed for a reason. If the benefits of the medication outweigh the fact that you have polio then you probably should answer that you have polio! The difficulty is that about 10 years ago some 'propaganda'—for want of a better word—was that, 'You shouldn't be on this,' or 'You shouldn't be on that,' and people were stopping necessary medications. The wording should be more like, 'You need to be aware that these medications may have some side effects. Consult your doctor.'

Ms Telford: I think Jill's recommendation would be great. I think that it could go a little bit further to also include some directions around nursing care, as well as medication. Another recommendation I would like to come out of this is that there could be retrospective funding, because it is often dangerous for us to have to wait, as you have heard. I do not understand the reason for not being able to have retrospective funding. We have paid it; we have our receipts. The funding comes through and you cannot get it. So I would like a recommendation to be that retrospective funding be available when the need has been established.

Ms Thomas: And urgent, I think.

Ms Telford: It is usually urgent.

Ms Thomas: I would like to make a quick point but it has totally gone out of my mind. Isn't that sad? Can I come back to it?

CHAIR: Please do.

Mr Doran: I would think that it would be very useful to have a question on neurological screen, certainly in the acute setting. It still does not solve the problem of how we get the other people outside the acute setting and the primary-care setting also to recognise those things and have the same knowledge base and the back story that conditions such as diabetes have, so that people understand why they are asking the question about diabetes, rheumatoid arthritis or what-have-you. The problem is that I do not think that that is robust enough at the moment.

Ms Thomas: I have kicked my polio brain into action! My point was about including a question on, 'Have you had polio?' It is a wonderful idea but it is not going to capture all the people that we are trying to capture. I just wanted to say that although it will make it more complex it will be a start. We still need a way of capturing people who are siblings of polio survivors or people who went to school with them, who may well have also contracted polio. We need a way—

CHAIR: It is more of a link in.

Ms Thomas: Yes, that is right.

Mr Dobson: Regarding medications that Jill mentioned—this is something you might like to note, sir—I suffer from rheumatoid arthritis. The medication that I take has been out of production for many months. So I have been now out of supply for over a month, and I am really starting to suffer with pain, which does not help the whole aspect of the late effects of polio. What can the government or the health department do when manufacturers get so sloppy with a condition as critical as rheumatoid arthritis?

CHAIR: There is no medication at all? Not even another brand?

Mr Dobson: Not one that is suitable for me. It is a gold based tablet. I used to be on an injection form, but they changed the base of that injection and it zonked me out.

CHAIR: That obviously effects your polio as well.

Mr Dobson: Yes. That is just one I wanted to mention.

CHAIR: Perhaps you could have a chat to Mark, privately, after about that specific issue.

Mr IRONS: John, you spoke about the situation with your back. Is there any operation that can help you fix those discs at all?

Dr Tierney: The operation they were proposing was on spurs. Discs, they can do—I do not know if they even do it in Australia, but it is possible to do one disc provided every disc above and below it is perfectly healthy. They are not to the point of doing anything about that. We will probably have to wait until developments in stem cell technology to actually correct this. It is quite a way away.

Mr IRONS: I thought you said Demtel technology!

Dr Tierney: No, stem cell.

Mr IRONS: The reason I ask is that I have had an operation where I have had triple replacement of discs. The lower three discs I had replaced in one operation.

Dr Tierney: Have you?

Mr IRONS: Yes, it was a seven-hour operation. It is an artificial disc—

CHAIR: It is bent where the spur is.

Mr IRONS: Yes, I guess. I am just saying, would that help? Dr de Graaff would know.

Ms HALL: He cannot diagnose you.

Mr IRONS: I know, I'm not asking. I am just saying, it is amazing what they can do nowadays.

Dr Tierney: The complexity of a polio back, which has a whole range of things wrong with it, stenosis, scoliosis and all sorts of other things, would make it more difficult than for someone who, say, had a sports injury and could have three. I would be delighted if someone could do that. I do not think we are quite to it.

Dr de Graaff: The question is very valid. It is good that you are lean, mean biochemical machine, because you are physically capable of doing that. You will do disc replacements in younger patients. The difficulty in a polio survivor situation is they have often had years of wear and tear with not necessarily the same forces that go through the back. They will have vertical forces, horizontal forces, torsional forces. The actual structure of the spine changes, so that you do not have the right biomechanics to replace a disc. If surgery is done it is usually done either for correction of the scoliosis or for nerve pain occurring in the legs. It is usually correctional or adjusting; not replacement.

CHAIR: What is straight forward for someone that does not have polio is very complicated for someone with polio. Very different.

Ms Telford: I have got a question for the person from the Department of Health and Ageing. The Medicare locals, I am wondering whether there is room for us to look at some recommendations, particularly around education and community awareness issues, for doctors as well as for other allied health professions, and perhaps the community. Is there a place? Could we be looking at Medicare locals as a way to start developing something?

CHAIR: The Medicare locals are meant to be looking at a holistic approach to the medical needs in a particular area. I think there is room for that. I think that is part of their focus.

Ms Telford: Could that be factored in?

CHAIR: That is currently part of their focus.

Ms Telford: Polio in particular.

CHAIR: I will let Mr Booth actually. There is a whole range. They have got a special diabetes section, they have got a whole range of different areas that they do look at.

Ms Telford: And is there a special polio—

Mr Booth: I was going to actually raise this quite a bit in the next session.

CHAIR: We have really gone onto supports and services, which is the next session. We will put this aside for the next session. We will end this session here now and reconvene. I know it says 2:30, but I think because there are a couple of members on the committee that need to leave by 3:30—

Ms HALL: I have got to leave at 3:00. I was told where I can catch my plane.

CHAIR: At 3:00, then. Is it okay with everyone if we have a five-minute break and reconvene at 20 past two? We actually got into services and supports, more so than management in the last session. We have covered a lot of those things.

Proceedings suspended from 14:14 to 14:21

CHAIR: This session aims to consider the supports and services available for those with late onset polio. It also aims to identify where deficiencies exist and where improvements could be made. We discussed a few of these things in the earlier session. We will use the same format again, going around the table and giving everyone an opportunity to make a five-minute statement, after which we will open up for questions.

In the previous session we spoke about recommendations. I remind members of the committee and the participants that we are having a round table discussion today and that we do not have the power to make recommendations. We will put out a discussion paper so that people who do make the decisions will be able to discuss what we are hearing today. Dr de Graaff wanted to make a comment before the close of the last session.

Dr de Graaff: I will make one comment and then defer to others. There was a question about consultation with the pharmaceutical industry. There is very little role at this point in time for direct pharmaceutical management of polio. Certainly some pharmaceuticals are used for symptoms such as pain and wear and tear on joints and the like. But in the actual treatment of the late effects of the post-polio syndrome process, there are no magical cures at this point in time.

CHAIR: Thank you. Mr Blaise Doran?

Mr Doran: There are a number of support groups which, in my opinion, do a very good job. There was a model in the UK some time ago that fizzled out—though I could be corrected on that—the expert patient group. The idea was that people with specific long-term health conditions got together and talked amongst themselves about strategies for how to manage and best keep themselves out of hospital and stop using healthcare systems as the way forward. While, as we have all heard, that relies a lot on voluntary support, I am not sure how sustainable, if you like, that is.

We have a multiple role, certainly in Victoria, in the provision of supports and services. We provide primarily assessment based services, as Liz Telford pointed out. That is what it was set up to do. Then we case coordinate with local service providers.

In other words, we make a comprehensive assessment, we come up with a potential management plan and we contact a local orthotist, a local physiotherapist, a local OT and so on and so forth to see what can be done for that person.

Obviously that requires us to then educate the group of health professionals who will be receiving that person as a referral. Does that work? There is varying feedback on that. I would say that when it works it works well but there are cases when it does not work well at all. I cannot really comment on why that might be the case because I do not know where it falls apart.

We try to provide education, as we have already touched upon. We also try to attend things. I will go to support groups and speak to them, whether they be in regional or metropolitan Victoria. There is no specific polio rehabilitation support service that I know of, although there is somewhere in Geelong that does provide a certain amount of rehabilitation.

CHAIR: A prime provider.

Mr Doran: A provider, yes. We have a very limited rehab role because of the number of people we know about and the number of people on the team. That is the way it works. We tend to take on the most complex people who need that kind of multiple approach from groups of clinicians. As I touched on before, what we try to do is encourage local service providers so that they have the skill set and rejig that skill set in a way that means when you are taking your rehabilitation approach it is not always the incremental one.

It may be that you have to cast a much longer line, expect people to make much slower progress and monitor much more carefully. I will point people to the current research evidence on what should be there, certainly from my own profession, in terms of exercise, strengthening and so on and so forth and we provide lots of information. The other support, I have mentioned before. I cannot emphasise enough how much the educational role is part of our treatment, across the board—hence why I am here, really.

Ms Telford: In terms of the supports needed, I went to the Better Health site. It listed possible rehab services that we should contact: speech therapy, OT, physio, pain clinic, orthotists, psychologists, respiratory health specialists and a couple of others. I want to make the point again that this is what is being recommended, but it is not available in the public system and it is very costly in the private system.

You are seeing a present, live example now of polio fatigue. I think a few others around the table—and sitting in the gallery—will be experiencing this as well. In terms of workplace support, I am in a fortunate position that I can organise my work day so that I work in blocks. This is a very unusual experience for me. In terms of support, we are not only looking at the needs for support in rehabilitation but also at keeping people working. I have had examples—from people present—where they have talked about the lack of understanding in the workplace, by employers and so on, of fatigue. Even without post-polio syndrome there is still tiredness from the extra energy that we have to exert to do things. As Arthur was pointing out, we do not necessarily look as though we are struggling, but it is difficult. I have had examples of people who were sacked—I am struggling with my words now, which is one of the effects of the fatigue—because of the lack of understanding in the workplace.

CHAIR: That is a particularly important issue. You want to give people the opportunity to continue working, but they need support and the employers need education to be able to support them. It is a good point.

Ms Telford: Exactly. And sometimes people need to be able to go part time. I have had examples where Centrelink has not accepted that people need to have a part pension, for example. It is not a black and white issue; they can continue working but they cannot continue working full time. That is one issue I wanted to raise. This is a bit off topic but somebody mentioned to me: what happened to e-health? This is something that was talked about a while ago by, I think, the federal government.

CHAIR: E-health is being implemented as we speak.

Ms HALL: The legislation has gone through.

Ms Telford: In terms of the previous topic, it is kind of linked to support. But if there was more knowledge and information shared through e-health—

CHAIR: Once e-health is up and running, it will be really good for the history of the patient.

Ms Telford: Yes, and also for those protocols. There is one more point that I want to make. It is to do with the workplace. There was an example, and I am not sure whether it is still the case, of the education department discriminating against people with polio in terms of their superannuation. This may have changed but I think it is worth mentioning. One of our members told us she moved to the Catholic education system because she would only receive five-eighths of her contribution when she retired plus she would be charged a 10 per cent administrative fee because it was perceived that there would be a greater administrative cost to them. So that person had to retire from her job as a teacher 15 years before she wanted to. She shifted from the education department because of this. I do not know whether anyone knows if that is still the current situation, but I think it is really worth exploring.

Ms HALL: Going back a number of years, a number of Commonwealth and state public sector employers put a certificate on the files of employees that they perceived had a disability—not only people with polio but all people who had a disability. If they left the job for that reason within a 10- or 20-year period, their superannuation would be reduced. With the changes in the way the superannuation system works I do not think that would come into play so much now.

CHAIR: It would also be an issue for disability discrimination law.

Ms HALL: I know, there are laws and things. Things have changed, but that is the way it was—

CHAIR: It would not be that way now though.

Ms Telford: The final point I want to make is about who is conducting this training and education and the support work. I think what is needed is resourcing of the community groups. We are all volunteers educating and doing community awareness and supporting the support groups. I think there needs to be much more in terms of resources for those groups.

Ms Liethof: I want to pick up on Liz's very last point in terms of resourcing the support groups. I wholeheartedly agree but I would also suggest that that support should come from a community development model rather than a business model because we have seen the odd situation where businesses, even not-for-profits, who take on polio not as a primary function but because it comes under the auspices of a disability have restructuring within their organisations and whatnot and, somewhere along the line, polio loses out.

I think that it is really important that, if polio support organisations are resourced, they are resourced for polio and are resourced by people that are specifically working for polio, as opposed to a business model. So that is just one thing.

The other thing that I wanted to raise was getting back to our younger polio survivors. I spoke to a 24-year-old Sri Lankan-born woman yesterday. She had polio at the age of three; she came out here with her family at the age of 1½. She is one of the 150 polio survivors who are seeing the orthotist Darren Pereira, who works very well with polio survivors. She did not want to be identified in her own right, and that is very typical of the very young polio survivors that we have at the moment; they do not want to identify as being part of this group. But, by the same token, they would really love to be able to identify each other and talk to each other. She is university educated and is looking for a job as an accountant; she is currently working as a call centre operator. Her biggest fear is, 'What's going to happen to me in the future? I'm 24 years old. I don't know what's going to happen.' I said, 'Would it help you to be able to connect with other young people?' because we know they are there but they are not putting their hands up. They do not want to be identified, because of the stigma and everything, especially from a lot of these Asian countries. Wherever it is it has always carried a mark of stigma attached to it. I said, 'What would be beneficial for you? Would you be looking at something like an online chat room or something like that?' She said, 'Yes, something like that would be really good.' So on one hand we have the older polio

survivors, 50 per cent of whom do not have access to the internet, but we have all these young people that do have access to the internet, and that is what they know.

So I am thinking that something like that is definitely a support mechanism that we need to consider for our country's younger polio survivors, and not only our country's younger polio survivors. As I said, there are a lot of organisations. I am looking at this particular research that came out of the National Rehabilitation Hospital in Washington DC. They have gone from having 4.9 per cent of their polio patients under the age of 50 in 2006 to 9.4 per cent in 2010. These people are generally migrants, but they have a whole range of different issues. They have a challenging mix of issues such as schooling and demands of work and raising a family; that is what came out of that. So they are a different demographic and they need a different type of support.

One of the other things that were raised by this particular person is that she has gone for various jobs and she believes one of the biggest problems that she has is accessibility to workplaces. I went to a division of general practice recently and there were four steps. I was thinking, 'That's typical.' This woman is actually in an electric wheelchair. There are so many people who are technically providing services, or even workplaces. This woman said, 'There was a perfect job and it was all good, but I couldn't get into the place.' So accessibility is another general issue that polio survivors are faced with, and that goes across the community.

CHAIR: Thank you very much.

Ms Thomas: One of the questions you posed in this section was: what support and services from the Commonwealth government exist? Not much apart from generic services—in fact, nothing apart from generic services, I should say. From state and territory governments, again there is not much apart from generic services, although there is funding through the state governments of South Australia, Queensland and Victoria. New South Wales gets zilch, and we are the biggest state.

The other point I wish to touch on is: what coordination exists between Polio Australia and the other state and territory bodies like the Post-Polio Networks. The polio community is an incredibly cohesive community. It is not like a lot of other disabilities where you might have 15 organisations in a state all providing some sort of support for that group of people with disabilities. In New South Wales there is one organisation; in South Australia there is one—maybe 1½—in Tasmania there is one; there are two now in Victoria; but they are incredibly cohesive. We all work very well together.

Polio Australia's management committee is made up of representatives from all those states. Our members are the state networks, and we all have a focus on providing services, support and information. Whatever the polio community needs is what we are there for. The people you have got around this table and observing in the room are all pulling in the same direction. You will not find what you find in the rest of the disability community where you have got organisations pulling in all different directions. I think that is very important.

CHAIR: Thank you very much.

Dr Peel: I have comments on some of the issues: firstly, what support and services exist. The post-polio support networks in Queensland are under the auspices of the Spinal Injuries Association and is a state organisation. They undertake advocacy for the post-polio population. Recently, they have been successful in at least two areas in obtaining a subsidy for heating and cooling costs because those of us with late effects of polio and post-polio syndrome are very sensitive to extremes of temperature, especially cold. The other area is in parking permits with the harmonisation of the disability parking permits across Australia. The Queensland polio population was facing the problem of whether they would qualify for the blue parking permits as Queensland had a two-tier system. The red parking permit was the lower grade of permit, and people with post-polio syndrome, like me, who just use a walking stick were only entitled to the red, which is the second-grade type of permit.

CHAIR: What is the difference between a red and a blue? You park in disabled spots.

Dr Peel: Sometimes you cannot. Some of the blues are specifically labelled as being for wheelchair users only. There is a drive to harmonise permits across Australia because Queensland only had the double tier.

Ms HALL: On harmonising, you were talking about the disabled sticker. What about taxi vouchers and eligibility for those? That is another area that often comes up.

Dr Peel: I do not know if they are trying to harmonise that, but we have a taxi subsidy scheme in Queensland.

CHAIR: Which you can use in each state.

Dr Peel: Which we can use in any state—you are right. That was another area of advocacy in which they have been successful, so that people with post-polio syndrome who just use a walking stick like me will be able to get a blue parking permit. With regard to—

Dr de Graaff: I have a quick comment: it is the way you fill out the form.

CHAIR: This is in Queensland though.

Dr de Graaff: No, it is in some of the councils in Victoria and interstate. The issue for me is twofold: firstly, the form does not take into consideration fatigue.

Dr Peel: No, it does not.

Dr de Graaff: I always fill in the high-falls risk after 25 metres because of weakness and fatigue and I rarely get it knocked back. That comes back to the person who is filling out the form having an understanding of what they are faced with.

Dr Peel: When I lived in Victoria, you filled out the form for me and I had a blue sticker. I go up to Queensland and I cannot get a blue sticker.

Dr de Graaff: Because I think you get around in thongs in Queensland.

Dr Peel: I actually kept using your blue sticker as long as I could. But you are right: it is how you fill out the form. And is about how they advocate it. The Spinal Injuries Association told me that they could not use the argument about fatigue or distance et cetera. They had to argue on the basis that we would need to be able to open our doors wide to get out with ease. In other words: on the basis you need a wide parking bay. That is how they got it through—just knowing how to run again with the transport department. That is it.

There is the Post-Polio Support Network, which of course is run by volunteers, under the umbrella of SIA. We repeatedly hear from the members in Queensland about how much they value and appreciate the information provided and the support given by the network.

The second point I want to make with regard to financial imposts upon those with LEOP/PPS is that we too conducted a survey—in fact, we based on the New South Wales survey—of polio survivors with LEOP/PPS in Queensland. Although 90 per cent of them had worked either part time or, for a period, full-time in their lives, few seemed to have any superannuation. It might have been because they were in an older age group, but it turns out that, of the 246 who responded, 52 per cent live on the age pension alone and 22 per cent live on the disability pension alone. That is 74 per cent who are in financial difficulty and find it very difficult to afford what we need, in terms of aids and renovating your house to cope with your particular requirements.

The third point I wish to make concerns the final point on the sheet, regarding the websites in both Queensland and Victorian health departments. The Spinal Injury Association's view is that the provision of information on the Queensland Health website has not really been successful. It is just not accessed. They do not know exactly why it is not accessed—and they have not done a survey—but all the anecdotal evidence suggests that the clinicians do not access that information. It may be that they do not know it is there, because Queensland Health do not seem to advertise it. It could also be that they are too busy. Perhaps it is because they only have one or maybe two patients in the category of polio survivors. For whatever reason, SIA officially say it has not worked. I do not quite agree with Blaise saying that it is an excellent document. I think it is too detailed, frankly. Polio Services Victoria's shorter document is also accessible via the Queensland Health website. I think that is a superior document in the sense that it is concise, it has dot points, and clinicians are much more likely to look at that. The late effects of polio document is 52 pages long and has 129 references, for goodness sake. It is more like an academic thesis—

Mr Doran: It is a beautiful piece of work.

Dr Peel: Although I am speaking on behalf of SIA. In that case, it is my personal opinion.

Finally, I would like to raise awareness about how difficult life becomes for certain people with LEOP post-polio syndrome by telling you a little—it will not take long—about the case report from Queensland. The woman concerned worked from 1983 to 1998 in the Commonwealth Public Service. She was able to walk several blocks at that stage and she coped quite well, with some limited help, with her housework. Then she developed late effects of polio. She was invalidated out of the Public Service and employment generally, as she puts it, in 1998 because of the onset of late effects of polio. She now requires a wheelchair for travelling distances of more than three or four metres. Her balance is severely compromised and she needs a personal support worker for six to seven hours every day.

She must use a bi-level CPAP machine to assist her breathing during sleep, and also she endures ongoing bladder leakage, for which she receives medication. She has increasing postural collapse and scoliosis, gross muscle weakness and extreme physical and mental fatigue. I quote her:

I currently have little or no access to doctors or other health professionals who have knowledge of the late effects of polio. I am 54 and I am more physically dependent than is my 91-year-old aunt. Where do I go? What do I do?

CHAIR: Thank you, Dr Peel. We now go to Dr John Tierney.

Dr Tierney: I think we have got to perhaps step back from this and have a look at the scale of this particular health issue on a number of levels. We know that there are hundreds of thousands of people in Australia who have the late effects of polio. We know what is going to happen as they progress through life, but most of them do not. They are not aware of the late effects of polio. That is why it is incredibly important that there is a community education program to let these people know the nature of the condition and the possible options they have.

At the next level we have groups in Australia that are organised to assist people with the late effects of polio. But as my colleagues here would tell you, the scale of what we are currently doing and the level of resourcing we currently have mean that if those hundreds of thousands of people suddenly discovered they did have the late effects of polio and came to us to seek assistance, we would be totally overwhelmed. The scaling of our resources to assist this group has got to go up dramatically.

At the third level, if we did have a larger organisation, we have got to refer them to allied health professionals, doctors, to assist them with that. And of course, as has come out during this discussion, a lot of the professionals do not know the nature of this condition and what the appropriate therapies are. So there is a massive education task for professionals as well. My point is scale. Everything is at a tiny level at the moment but if this was all done properly in an ideal world, the whole scale of it should be a lot bigger.

CHAIR: You have packaged it very well. Dr de Graaff.

Dr de Graaff: I have a couple of comments on what is clinically available. Blaise has spoken about what PSV offer, and that is fairly unique in Australia. In terms of the polio survivor in the community, if they have private health insurance they might go to a private rehabilitation setting. If they do not have private health insurance, if they are lucky they might get into a public setting where they could get some multidisciplinary input. That is only a small proportion of them. What generally precipitates them getting into a rehabilitative setting is another incident, such as replacement of a knee or a hip or a fall. So there is usually some calamitous process that leads them to being recognised as a polio survivor.

In terms of setting up the ideal situation, you would probably have a core group of a rehabilitation physician or the like, who works more in the medical model; a physiotherapist who is trained in neuromuscular-skeletal and ergonomics; an occupational physician, as Blaise mentioned; and an orthotist, as a minimum, with ready access to social work in psychology and speech pathology. One of the areas we have not talked about much today is problems with swallowing, in particular, and speech.

One of the big holes that we have, although we have talked about orthotists, is that there are not many podiatrists who are actually good at managing polio survivors. I always remember back a few years ago we had a special group that were together, and one of the gentlemen said that one day he woke up and he realised that he needed two different size shoes. No-one had actually gone through that process—a simple thing like that. There is often a skill needed in terms of footwear.

Then you can get into your more super specialities, such as respiratory physicians. One of the things that happen is that a lot of polio survivors, because of the mechanical problems associated with the chest wall, the scoliosis and the muscle weakness, have a thing called restrictive lung disease, but they get treated as if they have asthma so they get put on all these medications that are a total waste of time.

CHAIR: It is actually a lung disease, not asthma.

Dr de Graaff: Yes. It is a problem with the actual mechanics of chest expansion and closure because of the change in the structures around. There is also an increased incidence of obstructive sleep apnoea, which is one of the things that is grouped in polio and is recognized a little earlier, and there are sleep physicians—because it is a growing field—who are very interested in this. So those are a few of the areas that need to be included, apart from other super specialties such as orthopaedic surgeons and the like. I have certain orthopaedic surgeons who I send my polio survivors to because they think beyond the joint.

The challenge is to try and get these patients assessed early enough so that we do not get into the calamitous state where we actually need the extra resources to manage the decline and have rehab units that may be specialised down to a little bit of polio management, because most of them get picked up in a neurological unit, where they are overwhelmed by the strokes, the head injuries, the MS and such so they are put in the little corner. Their management is different because they are often coming in, as I mentioned before, with a chronic disease with an acute problem on top of it. Just a little thought in terms of where the management goes down the track, beyond the network of things that have been discussed here because that is well within my realm, within the actual clinical management of these people there should be a good coordinated team program that can help them move forward.

Dr Peel: I have just a quick comment, following on the need for multidisciplinary clinics. I wish to point out that there are 30 specific polio clinics across the United States and half of them are multidisciplinary.

Ms Telford: Picking up on comments of Steve de Graaff and others, I want to add that what we are looking at is the need for an empowerment model. I think Mary-ann Liethof talked about having a community development approach and at the moment there are not any funded community development workers. You can see by the people attending here today and the number of people that have sent in that we are a community that is very, very interested in being involved and that there is something very important about being heard and being part of the process of working out what we need, as has been mentioned. I think it is very important that, whatever sort of recommendations come up, the empowerment of the patient, the polio survivor, is taken into account.

CHAIR: Mr Howard, do you have anything to add?

Mr Howard: South Australia has been held up as a bit of a lucky place because our state government has seen fit to give us a grant of \$40,000. When that is spread over the number of members we have and the provision of hydrotherapy and stuff, it goes nowhere. One of the pools we go to costs us \$12,000 for the school year because there are two physiotherapists in the pool and there is also a person outside the pool in case somebody gets into strife, so over \$12,000 goes to that pool. The other pool that we had access to in the southern suburbs at Baliana was costing us over \$17,000 a year for the same process because we had to pay for the physiotherapist to travel from the northern suburbs to the southern suburbs. So, all of a sudden, there is over \$30,000 gone.

We try to provide our members with a voucher system. They can have three vouchers a year, at a value of \$40, to take to their massage person or whoever for extra services; but that goes nowhere. The grant is over \$50,000 now but we have to have our money auspiced through an organisation called DIRC—the Disability Information Resource Centre. They take over \$7,000 to auspice that money. We have an office at South Road, Hilton, and that costs us some money as well. I do not have that figure in front of me. But that is where we get up to the \$50,000.

They are just some facts and figures. Whilst on this topic, my secretary has to have the soles of his shoes built up so that they are strong enough to support his foot. Up until a few years ago that was easy: you would go and get some leather shoes. But you cannot get leather shoes anymore because everything that comes in has polyester soles. To get some specialist built boots made out of leather is beyond his financial means, and there is no support that I know of for that in South Australia.

CHAIR: Thank you very much. Our very last speaker is Mr Booth.

Mr Booth: I thought I would try and pick up on a few of the things that have been done today and talk about some of the primary care reform work that is going on—some of that is around education and funding—and also look at how to deal with complex chronic diseases. I will start off with the Medicare Locals. Medicare Locals, as people may know, are organisations that have been established across the country. There are going to be 62 of them established by 1 July. Medicare Locals have to undertake quite a range of different functions, and I will discuss a few of them that are particularly relevant here.

For the first time in primary care a single organisation will be responsible for looking at the primary care health needs and the health needs more generally of the population within their area. One of their key tasks is to come up with a population health plan. So they will have to consult with their communities. They will have to consult with their local user groups, health care professionals and other groups outside health care and build up a profile or picture of the health within the population that they look after.

They have also got a remit to join together all of the different primary healthcare groups that currently exist. As we know, there are very good relationships among them in some parts of the country but in other parts of the country you definitely get a GP view of the world, an allied health view of the world and a community worker view of the world. Medicare Locals will cut across all of that. They have a remit to pull together all of those different groups and to make sure that all the groups talk to each other and that services are put in place whereby patients can seamlessly move from one to the other.

This links into the population health planning side of things, because there will be a health plan produced for each Medicare Local area. There will be an analysis of the different professional groups that are there to meet those needs. Of course, what will come out of that will be gaps and areas which will need more emphasis put on them. It will be the Medicare Local's task to work with the different groups—the community groups and the healthcare professionals—to try and make sure that any gaps or deficiencies in their area are, as much as possible, addressed. The Medicare Locals will not be providers of services but they will be coordinating agencies and pulling together those kinds of things. So they have a real function in terms of pulling together what is going on in an area.

There is a very wide expectation around them in terms of consultation with different community groups and user groups. So they will have a variety of different advisory committees that will inform them of this. They will also have a remit to look at the linkages between primary care, secondary care and community based care and they will again work with local hospital networks and with different groups to try and pull things together across the whole area.

I think this is an exciting development really. It is trying to put into practice a lot of the things that we have been talking about: how do you effectively reorient a health system to one that moves away from acute care, just looking after people as they fall ill, to one that accepts that people have chronic conditions that they will live with for a significant number of years and also focuses on prevention? It is trying to put that into practice. I think Medicare Locals are a significant development in this area.

I briefly talked in the last session about multidisciplinary care and the move towards multidisciplinary care. A lot of the grant programs that we do in my area are primarily infrastructure grants, which are payments paid to practices or primary care infrastructure grants, rural and remote infrastructure grants, which are round mainly primary care facilities, general practice facilities, but also wider primary healthcare facilities extending the scope of what they can do so that they can provide more services. Every time we do a grant like that, we make it a condition that, if we give money out, it has to improve multidisciplinary care, it has to bring services together and it has to try and make the experience better for the patient. So we have that coming through as well.

Another area that there is work being done in is something called flexible funds. This is where the department is trying to make things easier and more simple. There have traditionally been a large number of grants and funding rounds that the department of health in Canberra has run. Instead of there being 120 separate grants rounds, those have been crunched down to 18, and there are flexible funds within there. There is a specific chronic conditions flexible fund, which people were invited to apply to for funding for different purposes. That will run on an annual basis. So that is happening as well.

In terms of funding, I accept what was said earlier about the federal government being general, but the vast majority of funding through the federal government is on the Medicare Benefits Schedule payments. A huge amount of money goes through that. There are specific areas within that, as you will know, around chronic disease items. Of course, there is also the Pharmaceutical Benefits Schedule.

There are two more things to briefly mention. One is that there is a primary healthcare framework being developed between the Commonwealth and the states, and that is to try and put a lot of the stuff that I been talking about here in terms of different models of care into one document. That is being completed as a single piece of work by the Commonwealth and the states together. Concurrently with that, there are bilateral strategies being put in place so that there is an agreement between the Commonwealth and each of the states and territories that says, 'How do we work best together to make sure that federal primary care funding and, typically, secondary care funding and community services work together fairly seamlessly as much as we can?' There is quite a bit of work going on there.

The final thing to mention is on the e-health side, which is the personally controlled electronic health record and the work that is going on there. So there is quite a bit of movement happening here that is relevant to this group and what is going on around here.

CHAIR: Thank you. I apologise to Mr Dobson, because I said we had our last contributor, but I missed Arthur altogether. Apologies; I hand over to you.

Mr Dobson: In Tasmania, we have no specialist services whatsoever. When people contact me, I try and find out what their main problem is. If it is silly buggers who are overdoing it, like I often am, I will try and tell them they have got to slow down. When they say, 'Isn't there a doctor I can see?' the only person I can refer them to is my friend beside me. It is hard to describe the difference that consultation with Steve has made to these people. They come back home and they sing his praises. I do not know really what he does to them, but they come back with a much more positive outlook on life after someone has actually listened to them and given them an assessment, given them a letter that they can take to their GP. I think this is what has helped these people the most. I have lost count of how many have come over. Most of them have paid their own transport costs, although they can get some financial assistance if they get the right referral from their GP to a specialist who then agrees that they will refer them to Steve.

From my point of view, looking at people in Tasmania as I know them, I think what they desperately need is some way to get an assessment sheet that they can confidently take when they go to hospital to avoid this overanaesthetisation and ridiculous physiotherapy attitudes and all these sorts of things. I think that would make the biggest difference to our few hundred polio survivors in Tasmania.

Yes, I have got a loud enough voice and I have got enough cheek to not put up with negative attitudes from medical staff. I was walking down the corridor in 5B, the surgical ward at the LGH, one day—and when I walk on a hard surface there is a distinctive clip-clop, clip-clop, clip-clop—and a nurse that had nursed me through both my hip operations stuck her head around the corner: 'Uh-oh! Who have we got here now that has had bloody polio?' She was the one that drew a face on my toenails when I was having a sleep after one of the operations. They did take notice, but you have got to be assertive—

CHAIR: And not everyone is assertive.

Mr Dobson: That is right. As the state chief health officer said, we have to be assertive. But, if we could have that assessment and give these people that confidence, it would make a world of difference—they cannot all come up on a plane to see Steve. That would be the biggest plus for us, and it would not cost the earth. It need not be a full-time clinic, as long as people were trained. I did have an arrangement worked out with one of Blaise's forebears that the team would come and do clinics at our three major hospitals twice a year for \$20,000. But the Tasmanian government would not support it, and when the Victorian government found out about it they said, 'No way, we fund Polio Services Victoria for Victorians.' But that would have solved the problem, because the people could have gone and got their assessment and it would have given them the confidence to go and say, 'Look, this is what you have got to do.' It would not cost the earth. I think it is a matter of the authorities needing to get over the psychological side of it and to realise that there is a group of people out there that desperately need help.

CHAIR: Thank you, Arthur, for your statement.

Mr Dobson: Thank you very much.

CHAIR: I have a question for Mary-ann. We did an inquiry into youth suicide a couple of years ago—and this is about engaging with young people—and what we found from the evidence given to us by young people, and we are talking 18-year-olds and 17-year-olds, was that each and every one of them told us that they got information about their depression and their other issues through the internet. They did not want to call anyone, they did not want to speak to someone face to face, and they did not want to be part of a group and have a discussion. They knew there was something wrong and they would search on the internet and liaise using the internet, which would put them in touch with services et cetera. We found this to be overwhelmingly the case with just about every young person we spoke with. So, if it is worth anything, I would say a young person with polio would have that same mindset, I suspect, in that they would rather interact on the internet with someone and then gradually take the next steps forward. That was just some of the research that we had from one of the previous inquiries.

Mark has to go and catch a flight, so we have to form a subcommittee. It having been moved, it will consist of Steve Irons and me.

Dr de Graaff: Just on the internet, it is a wonderful thing, but there is a lot of misinformation out there as well.

CHAIR: No, I am talking about setting up something that is absolutely—

Dr de Graaff: So it needs to be really structured—

CHAIR: These sites were set up by beyondblue and a whole range of others.

Dr de Graaff: It may well be that you do set up a blog system and things like that, and that opens up potential, particularly for those who are in remote situations. Never underestimate the person above the age of 65 adapting to computers. It is amazing what people can find. There is a common belief that they do not, but they do, very well.

The other thing that I think is very important gets back to what Arthur mentioned. When I write the letter back to the GP, which the patient always gets a copy of, I try to have some discussion about why these things are happening, to try and educate the GP at that time as well. One of the things we are trying to do in the faculty of rehab is have our trainee rehab physicians do that sort of thing as well—and not just with polio but with anything—in terms of looking at the functional implications of what is happening, so that, hopefully, with time, that information will get out there a little more. It is important that all of us have an educational role here.

CHAIR: I think you are quite right. Each and every person involved in this area has that educational role to play. You guys know that better than us.

Dr Peel: They say repeatedly that they educate their GPs—if they are willing to be educated.

CHAIR: We have heard a lot today about GPs not being in tune with the needs of people with polio or even the diagnosis of late onset polio. At university, when they are studying medicine, obviously there would be a section on polio, they would touch on polio?

Dr de Graaff: Very, very little, I have been told. The general emphasis is on more acute medicine. Chronic disease is more discussed post graduate, and that is because that is the real world whereas university is very much going through the design of managing critical situations. As Blaise mentioned before, there is somewhat more of an art in managing chronic illness. You still have to have your scientific basis, but then you have to use that to form your management plan. They are already squeezing medical courses down to five years from six years. That is where one of the dilemmas arises.

Ms Liethof: Over the last couple of years I have been invited to address first-year students at La Trobe University's orthotics unit, which has been fantastic.

CHAIR: That is the sort of stuff that really helps.

Ms Liethof: That sort of thing is fantastic. They have extended the invitation, and I am sure that they have got a lot out of it—as have I. That type of thing needs to be resourced more fully, and we need to be chasing up and doing talks in those types of situations as well—and not only by the likes of me. The beauty of this particular talk is that I am representing the polio survivor under these circumstances, but we also need to have orthotists talking to orthotists and physios talking to physios and so on and so forth, because they are not necessarily going to listen to a community development worker; it is peer-to-peer education that is required.

Mr Doran: That does occur to a greater or lesser extent. We do try and deliver. For example, if I go on a regional clinic, I will speak to whichever clinicians want to be spoken to—and not all of them do, and that is another issue which we will not touch upon now. My orthotist colleague does take on students from La Trobe University, and we recently brought in a polio survivor as a volunteer, to introduce them to someone in real life and get involved. Things are happening.

CHAIR: I suspect they will get a better understanding of polio than they would ever get from book learning.

Mr Doran: Touching on things that have been mentioned previously, one thing I am very curious about is many polio survivors from the 1950s pandemic. Migrants who have come in from European countries—as well as the Australians—would have had the opportunity for treatment at the beginning of their polio journey, and some will be getting an opportunity for treatment towards the latter half of their polio journey. There are a lot of recent migrants from places like sub-Saharan Africa, Afghanistan and Pakistan who may not have received any treatment at all as a child. I am really curious as to how we are going to manage those people from a clinical point of view, because we do not know how they are going to behave in later life, because they have not had treatment earlier in life.

I suppose the real challenge for us is that it is just anecdotal experience that the people who do come and see us from migrant communities at the moment tend to parachute in and then disappear. They use the service once and four years later might need to use the service again. They do not interface with health-care services very well. I am not sure why that is; maybe they feel that, although interpreters may be provided and we are trying to make it as unthreatening, if you like, as possible, it is still something that they necessarily want to engage in, and keeping below the radar is probably part of that. I do have some data on the spread of ages. Can I table that?

CHAIR: Is it the wish of the committee that we accept the data as evidence? There being no objection, it is so ordered.

Ms Liethof: I want to make a point about the Indigenous communities. We have no knowledge of polio in the Indigenous communities at all.

CHAIR: Is that a fact, that it does not exist?

Ms Liethof: The knowledge does not exist. We do not know. We would really love to see some research into polio in the Indigenous communities. We know that there is a clear underrepresentation of the CALD community in approaching support groups. We have virtually no Indigenous members in any of the polio support groups.

CHAIR: And no-one has undertaken a study, no PhDs?

Ms Liethof: I was talking to Professor Robert Hall the other night, who did a lot of work on doing statistics. He was based in the Northern Territory at some stage doing his research and even he scratched his head and said, 'No, I don't know anything about that.' It needs to be done.

Ms Telford: I think the point about people from non-English-speaking backgrounds not returning underscores the need for cultural sensitivity training in the organisations that are providing services. I do not think we can automatically know, as we have heard about today, what those needs are and what their perception is of the service when they receive it. It is more than just having interpreters.

CHAIR: It is about doing research for the future.

Ms Telford: That is right. The other point I want to make is about the education. I think most people I know who have had polio have been an example, an exhibit, and are quite happy to provide that service. But it is a service and it is at our own cost and there was no recompense at all.

Mr IRONS: To add to what you were talking about, Mary-ann, we had an inquiry a few years ago into regional and remote health, and polio did not come up at all. In all Indigenous communities we visited it never came up.

CHAIR: We visited many remote communities.

Mr IRONS: Just going on from what John said earlier about stem cell treatment, I would like to get on the *Hansard* record my understanding, and you can correct me or not, that stem cell treatment, if it was ever to work with polio, would require a hat-trick of creating new brain and spinal motor neurons, which is probably just a dream. What are your thoughts and where is the research into stem cells up to at the moment?

Dr de Graaff: Unfortunately what you read in the media is not really what happens in practice.

Mr IRONS: We know that already!

Dr de Graaff: The issue is that it is a long way from being fact. Certainly there is potential for targeting localised nerve groups that you may well have a role for stem cells and you are looking around the spinal cord to be able to do that. But we must remember that fatigue and other features are beyond the wasted limb. Yes, there probably is potential. When? We are still 15, 20 or 30 years away yet. But it is something that people will investigate any form of neurological disease for in this situation.

CHAIR: So we are a long way off.

Dr de Graaff: Yes, and for people to hold out hope for this it is probably relatively forlorn. We would be better to get on and try and manage the situation where it is now, minimise further damage and try and potentiate what is there.

CHAIR: When you are looking at diabetes, for example, and the cutting edge stuff that is happening at the moment with cancer research and a whole range of things, in polio what would be the most cutting edge stuff that is happening at the moment in terms of research?

Dr de Graaff: The orthotics, the compensatory tools.

Mr Doran: There are some researchers, particularly Kristian Borg in Sweden, who is investigating the use of intravenous immunoglobulin therapy to tackle the proposed neuroinflammatory component of post-polio syndrome. He reports there are some good effects, but the data is still in the balance, I think.

Ms Liethof: Some research that I have seen into stem cell therapy has occurred in India at rehabilitation stage. So we are talking about young people who are in the rehabilitation phase of getting over the acute virus. So stem cell therapy has worked to a certain extent under those circumstances. But in terms of what we are talking about, the later effects of polio, there has been nothing that I have seen in any of the research data to support that. But perhaps at acute phase that might help in developing countries.

Dr de Graaff: Probably the only other cutting edge area is that physiotherapy is looking at various ways of approaching neuromuscular insults and injuries which polio is part of. There are always new developments in the way we manage this sort of thing, particularly in terms of fatigue management and improving strength in areas where there have been damaged nerves. So that will continue to, hopefully, produce better outcomes for polio survivors in the long term, but it is a slow process.

CHAIR: Before I close today's round table I thank each and every one of you for participating and briefing us and giving us your statements, and in some cases your personal experiences. The contributions that you have made are very valuable to us today, as are your insights into polio. The committee will now go away and come up with a discussion paper, which I am sure the secretariat will ensure that each and every one of you has a copy of. I would also like to thank all the participants in the gallery that came to observe today. I thank you for coming along and putting up with us and hearing the committee and the participants as well.

It is very important that we have these round tables. We have had a series of them on a whole range of things in the past few years. Of course we have received evidence before, in the previous parliament, on polio from John and others. I know that many members on this committee have a keen interest in polio and do meet with members in their community on polio. Thank you very much for your contribution. It is really much appreciated and very valuable.

As I said, we will go away and develop this paper. Certainly if there is anything else that we may need that perhaps we did not ask today because we did not think of it, and it might come to us after, we may put a call in to you. Vice versa, over the next few weeks if there is something that you feel for whatever reason you did not

manage to ask today and it comes to you for a later time, please feel free to ring through and give us that information. If there is any more information you have, we certainly do welcome it. I thank my committee members, all the members in the gallery, Broadcasting for keeping an accurate record, the secretariat and my staffer Hannah Frank for putting it all together today and ensuring we ran a smooth round table.

Resolved (on motion by **Mr Irons**):

That this committee authorises publication of the transcript of the evidence given before it at public hearing this day.

Committee adjourned at 15:30