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Issues and conclusions

2.1 The roundtable into the late effects of polio/post-polio syndrome (LEOP/PPS) aimed to foster discussion between members of the House of Representatives Standing Committee on Health and Ageing and individuals either directly affected by LEOP/PPS and/or involved in treatment, support and advocacy. As noted in Chapter 1, discussion centred around three broad themes. These themes were:

- definition, diagnosis and prevalence;
- management and treatment; and
- services and supports.

Defining LEOP/PPS

2.2 One of the first issues considered during discussion relates to definitions and the use of terminology. Discussion indicated that there is inconsistency among researchers, health professionals and the wider community about the definitions of LEOP and PPS, and how and when each term is used. This inconsistency was particularly evident in research literature. While the international research literature predominantly refers to PPS rather than LEOP, the use of the term PPS varies from a narrowly defined, clinically diagnosed condition to a more general use of the term which encompasses a broader range of post-polio sequelae.

2.3 During discussion, consensus among participants was that LEOP is broadly characterised by a range of predominantly biomechanical symptoms, while PPS is characterised by a range of neurological symptoms. In general terms participants considered PPS to be a sub-category of LEOP, and the most severe manifestation of post-polio sequelae.[1]

2.4 According to researchers Choy and Lynch (2004), the distinction between LEOP and PPS is as follows:

> The late effects of poliomyelitis (LEOP) is a broad diagnostic term that encompasses the myriad of symptoms that a person with a history of poliomyelitis may experience. This can include symptoms that can be directly attributed to damage caused by the acute poliomyelitis episode, such as residual weakness, musculoskeletal imbalance, growth retardation, skeletal deformities, respiratory insufficiency or cold intolerance ... Another subcategory of LEOP is the post-polio syndrome (PPS). PPS is a variable combination of new progressive muscle weakness and other symptoms in survivors of paralytic poliomyelitis, with onset usually at least 15 years after the acute illness ... The cardinal symptom of PPS is new muscle weakness or muscle fatigability that gradually worsens.[2]

2.5 In 1998 Halstead, a prominent researcher on the subject who has published extensively over the years, defined PPS as a:

> ... neurological disorder that produces a cluster of symptoms in individuals who had recovered from paralytic polio many years earlier. These symptoms typically appear from 30 to 40 years after the acute illness. The major problems are progressive muscle weakness, debilitating fatigue, loss of function and pain, especially in muscles and joints. Less common are muscle atrophy, breathing problems, swallowing difficulties and cold intolerance.[3]

2.6 Mr Blaise Doran, physiotherapist and coordinator at Polio Services Victoria, Australia's only polio-specific clinical service, explained that the biomechanical issues which are a hallmark of LEOP come 'from a highly compensated neuro-musculoskeletal system'[4], which often manifests as osteoarthritis that develops more rapidly than would be expected in the general population. He also noted a range of secondary issues, including:

- lower general physical activity, resulting in muscle disuse and atrophy;

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[1] Polio Australia, Discussion Paper, p. 2.

[2] M Lynch, N L Choy, June 2004, The late effects of poliomyelitis in Queensland, *Australasian Epidemiologist*, p. 3.

[3] L S Halstead, April 1998, Post-Polio Syndrome, *Scientific American*, Vol 278, pp. 36-41.

[4] Mr Blaise Doran, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 6.

- an increased incidence of conditions such as osteopenia (a precursor for osteoporosis) and osteoporosis;
- reduced cardiovascular fitness that goes with being inactive;
- respiratory compromise from progressing scoliosis, kyphosis[5]; and
- obesity.[6]

2.7 Ms Gillian Thomas, President of Polio Australia, also noted that biomechanical symptoms of LEOP and the neurological symptoms of PPS often co-exist. As she explained in her opening statement:

> 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. ... 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.[7]

2.8 In terms of biomechanical symptoms associated with LEOP, Ms Thomas observed that they 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 ... an increase in falls, weight gain and a very pronounced age related weakness, which comes on earlier than expected.[8]

2.9 With respect to the neurological symptoms of PPS, Ms Thomas observed that these:

> ... 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.[9]

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[5] Scoliosis and kyphosis are curvatures of the spine.

[6] Mr Blaise Doran, *Official Committee Hansard*, Melbourne, 30 March 2012, pp. 6-7.

[7] Ms Gillian Thomas, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 3.

[8] Ms Gillian Thomas, *Official Committee Hansard*, Melbourne, 30 March 2012, pp. 3-4.

[9] Ms Gillian Thomas, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 4.

2.10 An important point raised relates to the association of paralytic and non-paralytic polio with LEOP and/or PPS. While definitions of PPS usually specify a clinical history of paralytic polio, a number of participants emphasised that LEOP (including the sub-category of PPS) can affect polio survivors who do not have a history of paralytic polio.[10] As Ms Thomas explained, even though some people who contracted polio did not display paralysis, they may still have suffered some degree of neurological damage. As a result, all polio survivors are potentially at risk of developing a range of post-polio sequelae, including the neurological symptoms more typically associated with PPS. In this regard Ms Thomas noted:

> 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 ... 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.[11]

2.11 Therefore, the population at risk of developing LEOP is much larger than the population of polio survivors with a clinical history of paralytic polio, who represent only around 1 per cent of polio survivors.[12]

Committee comment

2.12 Although there is some inconsistency with the definition and use of the terms LEOP and PPS, the Committee understands that two terms are not synonymous. Although the symptoms of LEOP and PPS frequently co-exist, it is generally understood that PPS is a sub-category of neurological symptoms existing within the wider array of post-polio sequelae which characterise LEOP.

2.13 While PPS seems to have gained currency, often being used preferentially in the international research literature, it would appear that the term LEOP does not have the same degree of acceptance. It may be that the existence of a generally agreed and accepted definition for PPS (discussed in more detail later) which is based on defined clinical criteria contributes to this.

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[10] Ms Gillian Thomas, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 4; See also: Mr Blaise Doran, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 10.

[11] Ms Gillian Thomas, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 4.

[12] Ms Gillian Thomas, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 3.

2.14 However, while not all people who experience post-polio sequelae will have the specific symptoms and clinical history needed to establish a definitive diagnosis of PPS, the Committee recognises the wider array of symptoms associated with LEOP can be seriously debilitating. As a result, the Committee believes that it is important that LEOP is accepted as a legitimate term which can be used to describe the full array of post-polio sequelae that can affect polio survivors, including those who do not have a history of paralytic polio. Therefore in this discussion paper the Committee generally uses the acronym LEOP/PPS to ensure that it is clearly understood that the Committee's considerations are inclusive, and address the needs of all those impacted by the longer-term consequences of polio infection. The exception will be where information presented during discussion pertains specifically only to PPS, as a sub-category of LEOP.

Prevalence of LEOP/PPS and population at risk

2.15 Determining the prevalence of LEOP/PPS is important in order to establish a clearer understanding of the potential demand for services and supports to assist with treatment and management. However, determining prevalence is difficult, particularly as there is no definitive diagnostic test for LEOP/PPS.

2.16 Estimating the population at risk of developing LEOP/PPS is also challenging. This is particularly the case as some polio survivors may be unaware of their clinical history, for example those who contracted polio during infancy, or who experienced very mild symptoms and were not diagnosed. Using medical records to establish a clinical history may also be of limited value, as records from prior to the 1960s (when endemic polio was essentially eradicated in Australia) are often inadequate, incomplete or missing.

2.17 As a result, there are no reliable estimates of the number of individuals in Australia with living with LEOP/PPS or of the population at risk of developing the condition. Gauging the prevalence of LEOP/PPS in Australia and the population at risk of developing the condition relies on estimates of the number of polio survivors living in Australia, and information from the international research literature on the proportion of polio survivors that develop LEOP/PPS.

2.18 In this regard, Ms Thomas told the Committee that Polio Australia estimates between the 1930s and 1960s, approximately 40 000 persons were diagnosed with paralytic polio in Australia.[13] However, as noted previously, only around one per cent of those who contracted polio experience paralysis. Consequently, the number of people with a history of polio and therefore at risk of developing LEOP/PPS will be much larger than implied by these data.[14]

2.19 Extrapolating from what is known to estimate the number of people who might be at risk of developing LEOP/PPS in Australia, Dr Stephen de Graaff, a Victorian based clinician, suggested:

> ... 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.[15]

2.20 In addition, estimates of the proportion of polio survivors who will develop LEOP/PPS vary. Acknowledging significant disparity in the research literature, probably reflecting inconsistent diagnostic criteria for LEOP/PPS between studies, Gonzalez et al reported:

> The prevalence of post-polio syndrome [also incorporating LEOP] has been reported to be between 20 per cent and 85 per cent of people who have had poliomyelitis.[16]

2.21 Further emphasising how little is known about the prevalence of LEOP/PPS in Australia, Ms Mary-ann Liethof of Polio Australia stated:

> ... 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.[17]

2.22 On several occasions during discussion, participants emphasised the importance of considering prevalence data in an epidemiological context. Although the majority of LEOP/PPS sufferers are Australians over the age of 50 years, being those who contracted polio prior to the introduction of an effective vaccine in the 1960s, there is also a population of younger Australians who are affected by LEOP/PPS or at risk of developing the condition. This younger population are those people who have contracted polio more recently (post 1960s to the present day), who are

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[13] Ms Gillian Thomas, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 3.

[14] Ms Gillian Thomas, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 3.

[15] Dr Stephen de Graaff, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 16.

[16] H Gonzalez et al, 2010, Management of post-polio syndrome, *The Lancet: Neurology*, Vol 9, pp. 634-42.

[17] Ms Mary-ann Liethof, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 6.

predominantly migrants to Australia from countries where polio eradication occurred later than in Australia or where polio continues to be endemic.[18] Ms Thomas explained the significance of this in her opening statement, noting that LEOP/PPS was likely to be an chronic health issue to be addressed into the future, observing:

> 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 ... 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.[19]

2.23 Participants also expressed concern that virtually nothing is known about polio in the Indigenous Australian population, and consequently whether Indigenous Australians are among those affected by LEOP/PPS or at risk of developing the condition.[20]

Committee comment

2.24 The Committee acknowledges the difficulties associated with determining the prevalence of LEOP/PPS and estimating the population at risk of developing the condition. From discussion during the roundtable the Committee concludes that although there are no robust data for Australia, it is likely that thousands of Australians are either suffering from LEOP/PPS or are at risk of developing the condition as they age.

2.25 The Committee understands that more needs to be done to determine the prevalence of LEOP/PPS and to assess the population at risk. As discussed in more detail later however, accurately determining the prevalence of LEOP/PPS will be contingent in the first instance on improving the capacity of clinicians and other health professionals to recognise the condition and confirm clinical diagnosis.

2.26 While acknowledging that not all polio survivors are aware of their clinical history, the Committee also understands that more needs to be done to identify as many polio survivors as possible to determine the population at risk of developing LEOP/PPS. Therefore the Committee

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[18] Ms Gillian Thomas, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 5. See also: Ms Mary-ann Liethof, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 6.

[19] Ms Gillian Thomas, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 4.

[20] Ms Mary-ann Liethof, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 36.

commends Polio Australia on its Australian Polio Register initiative.[21] Since its establishment in 2010 almost 1700 polio survivors have registered with the Australian Polio Register, providing basic demographic information (age, gender etc), as well as details of when and where they contracted polio.[22]

2.27 The Committee notes the suggestion made during discussion that data on polio survivors and people affected LEOP/PPS could be collected by the Australian Bureau of Statistics (ABS).[23] The Committee is aware that the ABS regularly conducts surveys to examine the health of Australians and surveys to assess levels and severity of disability affecting Australians.[24] Although none of the ABS health or disability surveys ask specific questions relating to a history of polio or to LEOP/PPS, chronic illness, long-term health conditions and disability are all extensively examined. While the suggestion for the ABS to collect data on polio survivors and LEOP/PPS has appeal, the Committee understands that there will be some limitations with the completeness of the data. In particular, the Committee realises that until the issues associated with establishing a diagnosis of LEOP/PPS have been addressed, regardless of the mechanism used to collect data, information on the prevalence of LEOP/PPS will be indicative at best. Notwithstanding this limitation, the Committee considers such data would provide some baseline information which is currently notable by its absence. The Committee comments further on data collection in its conclusion at the end of the discussion paper.

2.28 While acknowledging the potential value of data collected by the ABS, the Committee considers that an intensive research based approach will be needed to more accurately determine the prevalence of LEOP/PPS and the population at risk. Determining the prevalence of LEOP/PPS and estimating the population at risk in migrant communities and among Indigenous Australians would also require a targeted research effort. The Committee comments further on the need for research into LEOP/PPS later in the paper.

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[21] Ms Gillian Thomas, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 5.

[22] Polio Australia, http://www.polioaustralia.org.au/?page_id=3888, viewed on 7 June 2012.

[23] Ms Elizabeth Telford, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 11.

[24] See for example: ABS National Health Survey; ABS Australian Health Survey; ABS Disability, Ageing and Carers: Australia.

Impact of LEOP/PPS

2.29 One of the issues considered during discussion was the impact that LEOP/PPS has on sufferers, and on their families and carers. A number of participants shared their experiences of living with LEOP/PPS, highlighting in particular the difficulties that they face on a daily basis, as well as with managing their condition in the longer term. In particular, the Committee's attention was drawn to the following key issues:

- the physical effects of LEOP/PPS;
- the effects on social participation and emotional well-being; and
- the financial effects of LEOP/PPS.

2.30 While considered separately below, the Committee understands that the physical, social, emotional and financial impacts are in fact all interconnected.

Physical impacts

2.31 The physical impacts of LEOP/PPS can be significant. Many LEOP/PPS sufferers have a range of biomechanical and neurological impairments. Symptoms such as muscle weakness, muscle and joint pain impede mobility, one of the more obvious effects of LEOP/PPS. However, sufferers can also experience a range of other symptoms all of which impact on the quality of life, including fatigue, cold intolerance, difficulty swallowing and respiratory distress (including sleep apnoea).

2.32 Several participants explained how the physical effects of LEOP/PPS limited their capacity to undertake everyday activities. Activities mentioned included driving, and doing simple household chores such as cooking, cleaning, gardening and shopping.[25]

2.33 Ms Elizabeth Telford explained how fatigue experienced as a consequence of LEOP/PPS impacted on her capacity to engage in activities for prolonged periods, noting towards the end of the day's discussions:

> 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

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[25] Ms Gillian Thomas, http://www.aph.gov.au/Parliamentary_Business/Committees/House_of_Representatives_Committees?url=haa/leop pps/hearings.htm, opening presentation, slide no. 14.

> fortunate position that I can organise my work day so that I work in blocks ... Even without post-polio syndrome there is still tiredness from the extra energy that we have to exert to do things ... we do not necessarily look as though we are struggling, but it is difficult.[26]

2.34 Dr Margaret Peel explained how the physical effects of LEOP/PPS could make sufferers more vulnerable to secondary issues, illustrating her point by using the example of injury as a result of falls. Dr Peel noted:

> 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. ... With post-polio syndrome the reported fall rates are significantly higher—at least double that.[27]

2.35 As previously noted, other secondary issues arising as a result of the physical impacts of LEOP/PPS include reduced cardio-vascular fitness, increased levels of osteoporosis and obesity.

Social and emotional impacts

2.36 The social and emotional impacts on those with LEOP/PPS, their families and carers are also substantial. Reduced mobility and fatigue means that many people with LEOP/PPS find that they are less able to participate in social activities and community events. The impact of this is felt by affected individuals, and by their wider social networks. As Mr Arthur Dobson explained:

> Because I live alone, I am missing out on an awful lot of social life because I am not safe to drive [due to fatigue] ... but family members, extended family and social groups ... look at me and reckon I am all right ...[28]

2.37 Ms Thomas also explained that families can struggle to accept that a member of the family, often times a parent, may have reduced capacity as a result of their LEOP/PPS, telling the Committee:

> ... 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

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[26] Ms Elizabeth Telford, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 28.

[27] Dr Margaret Peel, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 21.

[28] Mr Arthur Dobson, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 24.

> anymore. It can really affect relationships. It obviously can affect your independence and your self-esteem.[29]

2.38 Ms Thomas proceeded to note:

> 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 ageing, and our carers are ageing as well.[30]

2.39 Participants also noted how maintaining employment, which due to fatigue and other physical limitations associated with LEOP/PPS can be challenging, is an important contributor to social and emotional well-being, assisting those affected to maintain social connectedness and preserve self-esteem.[31]

Financial impacts

2.40 The financial impacts of LEOP/PPS can be broadly categorised into the direct and indirect costs of disability. The direct costs for people living with LEOP/PPS include the costs of medication, treatment and mobility aids and devices. The indirect costs are usually associates with a limited capacity to maintain full-time or even part-time employment.

Costs of disability

2.41 For many, managing LEOP/PPS means that they necessarily incur additional costs. These include the cost of:

- mobility aids and other assistive devices;
- medications and treatment by medical and allied health professionals; and
- ancillary costs such as home and vehicle modifications.

2.42 Ms Telford gave a brief description of some of the aids and devices which are required by many LEOP/PPS sufferers and the associated costs, noting:

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[29] Ms Gillian Thomas, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 4.

[30] Ms Gillian Thomas, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 24.

[31] Ms Elizabeth Telford, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 8.

> The costs include assistive devices, braces, back braces, wheelchairs, scooters, CPAP [Constant Positive Airway Pressure] 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.[32]

2.43 Ms Telford also noted the costs associated with home and vehicle modification. She gave the example of a person living with LEOP/PPS:

> ... 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 get 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 ...[33]

Employment

2.44 As noted earlier for many people with LEOP/PPS maintaining employment can be challenging. Some LEOP/PPS sufferers may find that they are only able to work reduced hours, while others find that the severity of their symptoms prevents them from working at all.

2.45 While many people with LEOP/PPS strive to maintain employment in the face of considerable adversity for as long as possible, some found that they needed to bring forward their retirement.[34] As Ms Telford observed, retiring earlier than expected has significant financial implications.[35]

2.46 Even for those people with LEOP/PPS who feel able to maintain a level of employment, a lack of understanding from some employers can add to their difficulties. Participants referred to a number of cases where people with LEOP/PPS had experienced difficulties with finding or retaining employment as a result of poor workplace accessibility for people with

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[32] Ms Elizabeth Telford, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 8.

[33] Ms Elizabeth Telford, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 25.

[34] See for example: Ms Elizabeth Telford, *Official Committee Hansard*, Melbourne, 30 March 2012, pp. 8 and 29; Dr Margaret Peel, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 2

[35] Ms Elizabeth Telford, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 8.

restricted mobility or a lack of access to facilities suitable for people with a disability.[36]

Committee comment

2.47 The Committee recognises that the impacts of LEOP/PPS on its sufferers are substantial, encompassing not only physical impairment, but also social, emotional and financial effects. The Committee also recognises that the social, emotional and financial impacts extend beyond sufferers to affect the families, carers and wider social circles of people with LEOP/PPS.

2.48 In the Committee's view addressing the impacts of LEOP/PPS for sufferers, their families and carers will require a holistic approach comprising:

- improved recognition and diagnosis of LEOP/PPS;
- increased awareness of LEOP/PPS and its effects on sufferers, and also on their families and carers;
- enhanced research to further develop evidence-based best practice treatment and management; and
- provision of accessible health services, financial and social supports to assist people with LEOP/PPS and their families and carers.

2.49 Each of these issues is considered separately in more detail. However, before considering the first of these issues, improved recognition and diagnosis, the Committee wishes to address a specific issue relating to employment. The Committee was concerned by information presented during discussion which suggests that some employers may not adhere to their legislative obligations. Specifically, under Commonwealth, state and territory legislation, the Committee understands that employers are obliged to meet a range of legal requirements, particularly with respect to preventing discrimination on the basis of age, gender, race or disability.[37] For example, under the *Disability Discrimination Act 1992* (Cth) an employer must not directly or indirectly discriminate against an employee as a result of disability.[38] The Committee emphasises that employers should understand their obligations under various legislative instruments

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[36] Ms Elizabeth Telford, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 8.

[37] For example: *Age Discrimination Act 2004*, *Australian Human Rights Commission Act 1986*, *Disability Discrimination Act 1992*, *Racial Discrimination Act 1975*, *Sex Discrimination Act 1984.*

[38] *Disability Discrimination Act 1992* (Cth).

and actively pursue principles of equal opportunity and anti-discrimination. For employees with a physical disability, employers should also ensure that provision of access requirements, including disabled parking, toilets and access ramps, are maintained.

Diagnosis

2.50 Early diagnosis of LEOP/PPS is essential if affected individuals are to benefit from best-practice treatment and management for their condition. However, diagnosing LEOP/PPS is difficult. Firstly, as noted earlier, there is no definitive diagnostic test for LEOP/PPS. In the absence of such a test, clinicians arrive at a diagnosis through comprehensive medical examination, establishing a history of polio and elimination of other conditions which may present with similar symptoms. As a result diagnosis is often a drawn out process.

2.51 With respect to PPS specifically (though not LEOP), a set of widely accepted diagnostic criteria were established more than a decade ago. The criteria, provided at the roundtable discussion by Mr Doran are:

- Prior paralytic poliomyelitis with evidence of motor neuron loss, as confirmed by a history of the acute paralytic illness, signs of residual weakness and atrophy of muscles on neurologic examination, and signs of denervation on electromyography (EMG).
- A period of partial or complete functional recovery after acute paralytic poliomyelitis, followed by an interval (usually 15 years or more) of stable neurologic function.
- Gradual or sudden onset progressive and persistent new muscle weakness or abnormal muscle fatigability (decreased endurance), with or without generalised fatigue, muscle atrophy, or muscle and joint pain. (Sudden onset may follow a period of inactivity, or trauma, or surgery.) Less commonly, symptoms attributed to PPS include new problems with breathing or swallowing.
- Symptoms persist for at least a year.
- Exclusion of other neurologic, medical and orthopaedic problems as causes of symptoms.[39]

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[39] Mr Blaise Doran, Exhibit 1: Diagnostic criteria for Post-Polio Syndrome (PPS), 2001, *March of Dimes International Conference on Post-Polio Syndrome*, White Plains, NY, USA.

2.52 However, as noted earlier, not all people affected by post-polio sequelae will meet the criteria needed to establish a formal diagnosis of PPS. For example, not all polio survivors will have had a history of paralytic polio. Furthermore, although PPS may be considered the most severe presentation of post-polio sequelae, the symptoms of LEOP which occur in polio survivors without a history of paralytic polio can cause significant levels of disability.

2.53 Adding to the difficulty of diagnosing LEOP/PPS is that many affected individuals present with co-morbidities, including conditions frequently associated with the natural consequences of ageing, such as arthritis or osteoporosis. Before a diagnosis of LEOP/PPS can be considered, clinicians need to eliminate these other co-morbidities as the cause of symptoms. As explained by Ms Thomas:

> ... you cannot go out and get a blood test ... 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 ...[40]

2.54 Dr de Graaff also noted that the symptoms of LEOP/PPS are similar to a range of other conditions including rheumatologic diagnoses, such as fibromyalgia and chronic fatigue syndrome. Emphasising the importance of clinical experience, Dr de Graaff observed:

> Often a polio survivor will get lumped into that group ... 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 ... 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.[41]

2.55 These difficulties mean that many people with LEOP/PPS experience delays in receiving a confirmed diagnosis. Although it was evident from the experiences of roundtable participants that individual circumstances

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[40] Ms Gillian Thomas, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 8.

[41] Dr Stephen de Graaff, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 22.

vary, the Committee heard that the average time taken to achieve a LEOP/PPS diagnosis is six years.[42]

2.56 A number of participants who were eventually diagnosed with LEOP/PPS explained how they had initially been diagnosed with a range of other conditions. For example, Ms Telford told the Committee:

> ... 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.[43]

2.57 Dr John Tierney also spoke of his frustration at being initially misdiagnosed, noting:

> 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 ... 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.[44]

2.58 These experiences not only lead to frustration, but delays in diagnosis or initial misdiagnosis resulted in sub-optimal or even detrimental treatment and management of LEOP/PPS in the intervening period. For example, Ms Telford explained how initial misdiagnosis and inappropriate treatment had exacerbated her condition, saying:

> ... 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.[45]

2.59 In addition to the human costs associated with delayed diagnosis or misdiagnosis, Mr Doran also highlighted the costs to health systems noting:

> I think it is worth touching on the fact that, if you get an erroneous diagnosis at the start and it takes six or 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

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[42] Ms Elizabeth Telford, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 8; Dr John Tierney, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 9.

[43] Ms Elizabeth Telford, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 8.

[44] Dr John Tierney, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 8.

[45] Ms Elizabeth Telford, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 9.

> 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.[46]

Committee comment

2.60 The Committee recognises that diagnosis of LEOP/PPS is difficult, particularly in the absence of a definitive diagnostic test. While progress has been made with regard to establishing agreed and specific diagnostic criteria for PPS, the same cannot be said for LEOP. As a result, the Committee understands that many people living with LEOP/PPS continue to experience frustration, often waiting years to receive the correct diagnosis. In addition, it is concerning that misdiagnosis and inappropriate treatment and management of LEOP/PPS can exacerbate symptoms.

2.61 At a fundamental level the Committee considers that more research is needed to determine whether a definitive diagnostic test for LEOP/PPS can be established. The need for LEOP/PPS research is considered in more detail later. In addition, there is also clearly scope to improve the clarity of the diagnostic clinical criteria for LEOP, as has been done already for PPS.

2.62 Importantly, and in view of the need to establish a history of polio (paralytic or non-paralytic) to determine a diagnosis of LEOP/PPS, the Committee encourages polio survivors to advise health professionals of their history when seeking medical advice, diagnosis or treatment. The Committee notes suggestions for medical registration/admission forms in medical practices, allied health services and hospitals to include questions relating to a prior history of polio or a diagnosis of LEOP/PPS. While the Committee supports this suggestion in principle, it notes that responsibility for implementation currently resides either with the proprietors of private clinical practices and allied health services, or with state and territory government health departments.

2.63 Moreover, the Committee considers that new e-health initiatives will have an even greater potential to assist patients and health professionals to ensure that a history of polio or a diagnosis of LEOP/PPS is recognised.

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[46] Mr Blaise Doran, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 9. See also: Dr John Tierney, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 17.

Specifically, the Committee notes that in the 2012 Budget the Australian Government has committed to provide $233.7 million over three years to implement the National e-Health Program. The funding will ensure that from 1 July 2012, Australians will have the option of registering for a Personally Controlled Electronic Health Record (PCEHR). Patients who choose to participate will be able to securely access, and allow health care providers to access, their health information including information on their medical history. The intent of PCEHRs is to support more informed clinical assessments and decision-making, improve continuity of care and introduce efficiencies in health care service delivery.[47] The Committee considers the implementation of PCEHRs to be a significant development and strongly encourages people with a history of polio or a diagnosis of LEOP/PPS to register.

2.64 Notwithstanding the potential for PCEHRs to identify individuals with a history of polio, the Committee believes that educating health professionals and raising awareness of LEOP/PPS is likely to have the most significant impact on diagnosis.

Raising awareness and education

2.65 It is clear that there are a number of groups which would benefit from increased education and awareness of LEOP/PPS, and its implications. These groups are:

- health professionals, including GPs, other clinicians and allied health professionals;
- people affected by LEOP/PPS (sufferers, their families and carers);
- people with a history of polio and who are therefore at risk of developing LEOP/PPS; and
- the wider community.

Health professionals

2.66 Ensuring that clinicians and allied health professionals are aware of, and educated about, LEOP/PPS will improve the chances of earlier diagnosis and implementation of best practice treatment and management.

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[47] Australian Government, http://www.budget.gov.au/20123/content/bp2/html/bp2_expense-12.htm, viewed on 5 June 2012.

However, discussion suggested that some health professionals in Australia are unaware of LEOP/PPS, or as outlined by Mr Doran, in some cases even sceptical about the existence of the condition:

> 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.[48]

2.67 Some participants suggested, with the eradication of polio in Australia, that health professionals in practice are less aware of polio as a problem, and therefore of the risks of developing post-polio sequelae. It is likely that this has translated into limited education about polio during undergraduate training for physicians and allied health professionals. As Dr de Graaff explained, medical students learn little about chronic diseases in their undergraduate training, with the emphasis being more on the management of 'critical situations'.[49] As a result, the Committee was told that many health professionals may not even consider LEOP/PPS as a possible diagnosis.

2.68 Furthermore, the Committee heard that even if advised by people living with LEOP/PPS of their diagnosis, a generally poor understanding of the condition meant that some health professionals were unaware of best practice treatment and management. During discussion Dr Tierney and Mr Dobson told of their own experiences with physiotherapy following surgery. Both had been advised to follow rehabilitation regimes that were inappropriate for people with LEOP/PPS, and which if followed could have exacerbated their symptoms.[50] Ms Telford told of three different cases where a lack of understanding of LEOP/PPS among health professionals had resulted in inappropriate management. In one of the cases the patient died as a consequence.[51]

2.69 Several participants related examples which illustrated a lack of awareness among health professionals of the increased sensitivity of polio survivors to anaesthetics and other medications. Worryingly, these cases also indicated a dismissive attitude among some health professionals to

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[48] Mr Blaise Doran, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 11.

[49] Dr Stephen de Graaff, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 36.

[50] Mr Arthur Dobson, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 11; Dr John Tierney, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 13.

[51] Ms Elizabeth Telford, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 14.

these risks, even when advised by the patients concerned. For example, Dr Tierney recounted his experience of recent surgery, telling the Committee:

> I recently had an operation. It had nothing to do with polio, but I was involved with an anaesthetist. [Polio Services Victoria] 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 blasé.[52]

2.70 Mr Dobson’s experience with surgery, while quite different, also poignantly illustrated the importance of ensuring that health professionals are well informed:

> 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 ...[53]

2.71 To reduce these risks Ms Telford suggested introducing hospital protocols saying:

> 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

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[52] Dr John Tierney, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 14.

[53] Mr Arthur Dobson, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 15.

> somebody identifies themselves ... there should be protocols that are followed.[54]

2.72 A number of participants observed that some state and territory health departments and services already provide web-based resources for health professionals. For example, on its website Queensland Health provides information on LEOP/PPS for health professionals, including a comprehensive manual titled *The late effects of polio: information for general practitioners*.[55] Reference was also made to on-line resources developed for health professionals by Polio Services Victoria, Australia's only publicly funded LEOP/PPS specific service.[56]

2.73 In her introductory statement, Ms Thomas referred to awareness raising initiatives supported by Polio Australia, drawing attention in particular to Polio Australia's Clinical Advisory Group which:

> ... includes a range of health professionals, who cover lots of different areas, such as rehab, physio, orthotics, psychology, respiratory and research ... They are tasked with standardising quality information and producing resources for health professions and for the polio community.[57]

2.74 Identifying the need to ensure that GPs, as a frequent first point of contact for polio survivors, are aware of LEOP/PPS, Ms Telford noted:

> 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.[58]

2.75 Ms Liethof also noted that there is evidence of growing interest in some allied health disciplines to include information on LEOP/PPS for undergraduate students. Specifically she told how she had been invited

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[54] Ms Elizabeth Telford, *Official Committee Hansard*, Melbourne, 30 March 2012, p 14.

[55] Queensland Health, http://www.health.qld.gov.au/polio/html/manual_download.asp, viewed on 6 June 2012, 'The late effects of polio: information for general practitioners', 2001.

[56] Polio Services Victoria; http://www.svhm.org.au/services/polioservicesvictoria/Pages/Resources.aspx, viewed on 5 June 2012. See also: Dr John Tierney, Exhibit 3: Anaesthesia & Surgery: a guide for people who have had polio.

[57] Ms Gillian Thomas, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 5.

[58] Ms Elizabeth Telford, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 8.

now on two occasions to speak on LEOP/PPS to La Trobe University's undergraduate orthotics students.[59]

Community awareness

2.76 While raising awareness of LEOP/PPS amongst health professionals is critical, there is also the need to raise awareness in the wider community. Specifically, awareness needs to be raised among:

- those affected by LEOP/PPS, including sufferers, their families and carers;
- polio survivors who are at risk of developing LEOP/PPS; and
- the wider community, which will include some people currently living with LEOP/PPS who have been misdiagnosed, as well as other at risk of developing LEOP/PPS but who are unaware of their risk, having no knowledge that they have a history of polio.

2.77 Awareness of LEOP/PPS within the affected and at risk communities is important for a number of reasons. Firstly, individuals with a diagnosis of LEOP/PPS need to access good quality information to help them adapt, and understand how to best manage their condition. Likewise, families and carers of people with LEOP/PPS need to be similarly informed, so that they have a better understanding of the impact of the condition on the affected individuals and the kind of support and assistance needed.

2.78 Increasing community awareness could also help to identify polio survivors with symptoms of LEOP/PPS who, being unaware of the condition, may not have mentioned a history of polio to their GPs or other health professionals providing treatment. As Ms Telford explained:

> 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.[60]

2.79 Dr Tierney highlighted the possible extent of this issue, and also emphasised the importance of raising awareness of LEOP/PPS as a possible diagnosis for this group, observing:

> We know that there are hundreds of thousands of people in Australia who have the late effects of polio. We know what is

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[59] Ms Mary-ann Liethof, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 36.

[60] Ms Elizabeth Telford, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 8.

> 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.[61]

2.80 Polio survivors who have not yet developed symptoms of LEOP/PPS also need to be made aware of the condition, so that they can make adjustments to their lifestyle and behaviour to minimise their risks of developing the condition. All polio survivors, regardless of whether they experienced paralytic or non-paralytic polio, should be proactive in advising health professionals of their clinical history.

2.81 As noted earlier, a number state government health departments and services have web-based resources which provide information on LEOP/PPS. While some is intended to inform health professionals, resources also include information that is targeted to community and consumers.[62] Polio Australia and state-based polio networks also play a vital role in dissemination of information to polio survivors, their families and carers.[63]

2.82 Noting that a large proportion of Australia polio survivors contracted polio prior to the 1950s, many are now over 50 years of age. In this context Ms Telford emphasised the importance of disseminating information via a range of media, explaining:

> 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.[64]

2.83 Participants also noted the need to use appropriate mechanisms to engage effectively with polio survivors from migrant populations. Importantly, in addition to considering linguistic and cultural differences, polio survivors

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[61] Dr John Tierney, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 32.

[62] See for example: State Government of Victoria, Better Health Channel, at: http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Polio_symptoms_in_later_years?open, viewed on 5 June 2012.

[63] The state and territory network comprises: Post-Polio Network NSW; Post Polio Network Victoria; Post Polio Network Tasmania Inc; Polio South Australia Inc; Post Polio Network of Western Australia Inc; and Spinal Injuries Association Inc (Queensland).

[64] Ms Elizabeth Telford, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 13.

from migrant backgrounds are generally younger than those who contracted polio in Australia, reflecting global regional differences in eradication of polio, and the fact that in some countries polio is still an endemic or episodic epidemic reality. Ms Liethof provided the example of young Sri-Lankan born polio survivor, explaining:

> 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. ... 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?' ... '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.'[65]

2.84 Ms Liethof concluded:

> 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.[66]

2.85 Discussion also highlighted the need for education within the wider community as increasing awareness of LEOP/PPS will help people to better understand the impacts on sufferers and on their families and carers. Of relevance here is the Australian Government Department of Health and Ageing’s (DoHA’s) newly streamlined flexible funds program referred to by Mr Mark Booth. Operational since 2011, the Chronic Disease Prevention and Service Improvement Flexible Fund provides funding on annual basis to support a range of activities under the following four priority areas:

- prevention across the continuum;
- early detection and appropriate treatment;
- integration and continuity of prevention and care; and

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[65] Ms Mary-ann Liethof, *Official Committee Hansard*, Melbourne, 30 March 2012, pp. 29-30.

[66] Ms Mary-ann Liethof, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 30.

- self management.[67]

2.86 The range of activities supported under these priorities is extensive. It includes health promotion activities such as building evidence to support the knowledge base, facilitating best practice, raising community awareness and developing consumer education tools and resources.

Committee comment

2.87 The importance of raising awareness of LEOP/PPS was raised frequently during discussion. As outlined above, raising awareness amongst clinicians and allied health professionals is critically important to ensure timely diagnosis and treatment that is based on best practice. While the Committee understands that the focus of undergraduate training for medical practitioners primarily focuses on addressing acute situations, an increasing recognition of chronic conditions and their impact on the health of an ageing population may provide the context for consideration of LEOP/PPS during undergraduate training. In this regard the Committee was encouraged to hear that La Trobe University had invited Polio Australia to speak on LEOP/PPS to first year undergraduate orthotists. However, the Committee believes that more should be done to ensure that curricula for medical students, and for other relevant health professionals, include information on LEOP/PPS as a possible diagnosis and on best practice treatment and management.

2.88 Clearly different communication strategies will need to be used to reach health professionals already in the workforce. In this respect, the Committee commends the work of Polio Australia's Clinical Advisory Group which has been tasked to produce standardised, quality information on LEOP/PPS to inform health professionals, as well the wider community. The Committee notes the potential for awareness raising activities, and professional capacity building activities to be supported under DoHA's Chronic Disease Prevention and Service Improvement Flexible Fund. Therefore, the Committee encourages Polio Australia, either in its own right as an incorporated entity or in partnership, to investigate options of applying for funding under this initiative to promote awareness of LEOP/PPS.

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[67] Australian Government Department of Health and Ageing (DoHA), http://www.health.gov.au/internet/main/publishing.nsf/Content/7398759FFA7FC7FECA25794B001E29E2/$File/CDPSI%20Fund%20Guidelines%20FINAL%20171111.pdf, viewed on 1 June 2012.

2.89 While some state government health departments already have web-based resources which provide information on LEOP/PPS, the Committee notes that there is no information available on the DoHA website. The Committee considers that DoHA should take action to address this deficiency by providing a nationally co-ordinated web-based repository of information on LEOP/PPS.

2.90 Furthermore, the Committee understands that reforms to primary health care, notably the establishment of GP Super Clinics, will provide additional opportunities to enhance dissemination of information on LEOP/PPS and education. While GP Super Clinics are principally being established to support the delivery of multi-disciplinary primary health care, their remit also entails support for health promotion and illness prevention, as well as capacity building for the health workforce.[68] In view of this, the Committee considers that dissemination of information on LEOP/PPS and education of health professionals would constitute an integral part of the health promotion and continuing professional development functions supported by GP Super Clinics.

2.91 GP Super Clinics also have a role in promoting integrated and consistent care across services. Therefore, the Committee suggests that GP Super Clinics could assist services to establish and adopt standard treatment protocols for polio survivors, a significant issue for people with LEOP/PPS. With regard to engagement with the wider community the Committee notes that the service delivery model for GP Super Clinics also includes provision of a health resources library for patient education.[69]

2.92 Finally with regard to raising awareness, the Committee recognises the need to tailor information and communication strategies to enhance engagement with particular groups. Therefore, in addition to web-based resources, the Committee believes that information on LEOP/PPS should be provided in printed form, and promoted through community newsletters, radio and community announcements on television so that it is accessible to all people, including those who do not use the internet.

2.93 Furthermore, the Committee is also aware that specific communication strategies will need to be applied to reach migrant polio survivors, particularly as it seems that this population has limited engagement with the health system. Therefore information on LEOP/PPS needs to be

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[68] DoHA, http://www.health.gov.au/internet/main/publishing.nsf/Content/pacd-gpsuperclinic-about, viewed on 1 June 2012.

[69] DoHA, http://www.health.gov.au/internet/main/publishing.nsf/Content/pacd-gpsuperclinic-about, viewed on 5 June 2012.

available in languages other than English, and dissemination strategies should include the use of multi-cultural media and engagement with multi-cultural community groups.

Treatment and management

2.94 The appropriate treatment and management and of LEOP/PPS is vital to ensure that affected individuals continue to enjoy the best quality of life for as long as possible. As noted, delayed or inappropriate treatment and management of LEOP/PPS can be detrimental. There are broadly two possible approaches to the treatment and management of LEOP/PPS. These are:

- pharmaceutical treatments; and
- physical therapies.

Pharmaceutical treatments

2.95 Although the principle focus of the roundtable discussion was on physical therapies, pharmaceutical treatment options for LEOP/PPS were considered briefly. While there is currently very little evidence to support a direct role of pharmaceuticals in the treatment of LEOP/PPS, Ms Thomas referred to a recent review of treatments for PPS published by the Cochrane Collaboration.[70] The review, which examined evidence relating to the effectiveness of nine pharmacological interventions, concluded that there was insufficient evidence to draw definitive conclusions on their efficacy and that further investigation was needed.[71]

2.96 Nevertheless, as explained by Dr de Graaff:

> 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.[72]

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[70] Cochrane Reviews are systematic reviews or meta-analyses which summarise and interpret the results of medical research.

[71] F S Koopman et al, Treatment for post-polio syndrome. Cochrane Database of Systematic Reviews 2011, Issue 2, Art. No: CD007818. DOI: 10.1002/14651858.CD007818.pub2.

[72] Dr Stephen de Graaff, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 28.

2.97 Dr de Graaff commented further on the complex care requirements of many LEOP/PPS sufferers, noting that particular care was required when considering pharmaceutical treatments to address co-morbidities in this group. In response to concerns that some pharmaceuticals used to treat co-morbidities exacerbate LEOP/PPS, Dr de Graaff emphasised that professional judgement was required to determine whether the benefits of the medication outweighed the side effects for LEOP/PPS sufferers.[73]

Physical therapies

2.98 Physical therapies are much used in the treatment of LEOP/PPS. In considering physical therapies the following key issues were raised:

- the importance of physical therapies which are appropriately structured to take into account the unique requirements of people with LEOP/PPS;
- the need to empower people with LEOP/PPS to manage their own condition as much as possible; and
- the importance of a multidisciplinary and holistic approach to treatment and management of LEOP/PPS.

2.99 As noted earlier physical therapies which alleviate symptoms of other chronic conditions, if used to treat people with LEOP/PPS may actually be detrimental. In particular participants commented on the need to carefully manage muscle strengthening and exercise programs to ensure that additional muscular damage does not occur. As Dr Tierney explained:

> 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.[74]

2.100 Dr Tierney described how his own exercise regimen is designed to optimise the benefits of gentle exercise and reduce the risks of over-exertion, telling the Committee:

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[73] Dr Stephen de Graaff, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 26.

[74] Dr John Tierney, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 8.

> 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.[75]

2.101 While noting that many people with LEOP/PPS ultimately manage much of their own physical therapy, Mr Doran cautioned that polio survivors first had to overcome a tendency to strive to achieve over and above what is required. In this regard Mr Doran noted:

> ... 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.[76]

2.102 Agreeing with this observation, and in view of the potentially detrimental effects of over-exertion, Dr de Graaff suggested:

> ... that 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.[77]

2.103 In addition to supporting and empowering people with LEOP/PPS to manage their own physical therapy, the critical importance of a multidisciplinary approach involving medical practitioners and allied health professionals including physiotherapists, osteopaths, podiatrists and orthotists was raised during discussion.[78]

2.104 The roundtable heard how DoHA is working towards promoting a multidisciplinary approach to care. As Mr Booth explained:

> ... one of the things that we are trying to do at a Commonwealth level is encourage a move towards multidisciplinary care, really

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[75] Dr John Tierney, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 18.

[76] Mr Blaise Doran, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 12.

[77] Dr Stephen de Graaff, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 16.

[78] Ms Gillian Thomas, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 4; Mr Blaise Doran, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 17; Dr Stephen de Graaff, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 32.

> 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.[79]

2.105 Mr Doran observed that in many cases the most effective treatment for people with LEOP/PPS was not just multidisciplinary, but also to some extent 'transdisciplinary', explaining:

> ... 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.[80]

2.106 Also, as previously noted, people with LEOP/PPS often have co-morbidities and complex care needs. Therefore, advocating a multidisciplinary approach Dr de Graaff also emphasised the importance of good coordination in the clinical management of LEOP/PPS from all involved.[81]

Committee comment

2.107 The Committee appreciates the fundamental importance of appropriate treatment and management of LEOP/PPS. Although people with LEOP/PPS present with a range of symptoms which are common to some other chronic conditions, the generally accepted approaches to treatment may not be suitable for LEOP/PPS, and may even be detrimental. The Committee understands therefore that treatment and management of LEOP/PPS symptoms must be tailored to meet the specialised needs of this group. Optimal treatment and advice on best practice management of LEOP/PPS is of course dependent on affected individuals receiving an accurate and timely diagnosis in the first instance.

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[79] Mr Mark Booth, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 17.

[80] Mr Blaise Doran, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 17.

[81] Dr Stephen de Graaff, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 32.

2.108 Although there is clearly a need for further research to establish the potential effectiveness of pharmacological treatments and determine best practice parameters for physical therapies, based on discussion at the roundtable the Committee feels able to make number of general observations. Firstly, raising awareness of LEOP/PPS among health professionals is crucial. Furthermore, access to good quality information and ultimately evidence-based best practice guidelines for the treatment and management of LEOP/PPS is also important.

2.109 Secondly, developing best practice treatment and management strategies must also take into account the individual circumstances of people with LEOP/PPS. Reviewing how each individual responds to treatment and physical therapies is an important factor in determining what is best for that person. As it is affected individuals who are best able to monitor their own responses to treatment, the Committee believes that people with LEOP/PPS, as well as their families and carers, should be encouraged to play an active role in managing their own condition.

2.110 Thirdly, the Committee acknowledges the importance of a multidisciplinary and holistic approach to the treatment of LEOP/PPS. The Committee notes that elements of the Australian Government's National Health Reforms are likely to promote multi-disciplinary care in the primary health system. Again the Committee emphasises the role of GP Super Clinics, noting:

> GP Super Clinics are a key element in building a stronger national primary health care system including a greater focus on health promotion and illness prevention and better coordination between GPs and allied health services, community health and other state and territory funded services.[82]

2.111 Furthermore, PCEHRs discussed earlier also have the potential to enhance multidisciplinary care by improving coordination and collaboration between physicians and allied health professionals.[83]

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[82] DoHA, http://www.health.gov.au/internet/main/publishing.nsf/Content/pacd-gpsuperclinic-about, viewed on 15 May 2012.

[83] DoHA, http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/pcehr-why-do-you-need, viewed on 16 May 2012.

Services and supports

2.112 Access to clinical and allied health services, financial support and peer support is crucial to cater for the needs of people with LEOP/PPS, as well as for the needs of their families and carers. In the main, the delivery of primary health care services is the domain of state and territory governments. The Australian Government, while not directly providing services, plays a role in policy development and is responsible for the implementation of new programs such as GP Super Clinics and the new Medicare Locals.

Access to services and supports

2.113 People with LEOP/PPS can access the full range of generic health services available to all Australians. However, there is only one publicly funded LEOP/PPS specific service operating in Australia – Polio Services Victoria. Physiotherapist and coordinator of Polio Services Victoria, Mr Doran summarised its role as follows:

> We provide primarily assessment based services ... we make a comprehensive assessment, we come up with a potential management plan and we contact a local orthotist, a local physiotherapist, a local O[ccupational] T[herapist] and so on and so forth to see what can be done for that person.[84]

2.114 Although not a LEOP/PPS specific service, Ms Thomas also referred to a late effects of disability clinic operating in Western Australia, noting:

> 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.[85]

2.115 In most states and territories people with LEOP/PPS have to rely on generic health services. For example Mr Dobson noted that Tasmanian based LEOP/PPS sufferers had to travel to Victoria if they wanted to consult with a clinician with specialist knowledge of the condition. As he explained:

> In Tasmania, we have no specialist services whatsoever. When people contact me, I try and find out what their main problem is. If

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[84] Mr Blaise Doran, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 28.

[85] Ms Gillian Thomas, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 19.

> 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 [Dr Stephen de Graaff].[86]

2.116 Also, even where polio specific services are available, participants noted that engagement with polio survivors from migrant communities was challenging. In this regard Mr Doran observed:

> I suppose the real challenge for [Polio Services Victoria] 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.[87]

2.117 Ms Telford commented further on this issue, noting that in her view there is a need for more than just interpreter services to improve engagement with migrant polio survivors, saying:

> 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.[88]

2.118 As many people with LEOP/PPS will experience muscle and joint issues which affects their mobility, they frequently need to access services provided by allied health professionals. While not an exhaustive list, people with LEOP/PPS may need the services of physiotherapists, occupational therapists, orthotists, orthotic technicians and podiatrists.[89]

2.119 Despite the importance of services provided by allied health professionals, participants reported that access to these services was limited due to

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[86] Mr Arthur Dobson, *Official Committee Hansard,* Melbourne, 30 March 2012, p. 34.

[87] Mr Blaise Doran, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 36.

[88] Ms Elizabeth Telford, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 36.

[89] Ms Elizabeth Telford, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 28.

workforce shortages. As a result people with LEOP/PPS sometimes experienced significant delays when seeking assessment of their needs, access to rehabilitation services and personalised mobility aids and devices. For example, Ms Telford told how shortages of experienced orthotists and orthotic technicians led to lengthy delays in receiving mobility aids and devices.[90] Ms Thomas also illustrated the kind of delays that can be experienced, reporting:

> On the waiting time for an orthotic, the person who actually runs our 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.[91]

2.120 In responding to issues of gaps in services more broadly, Mr Booth briefly described the aims of the Australian Government's Medicare Locals program. Mr Booth advised that under the program each Medicare Local, in consultation with the local community, will be expected to produce a population health plan. He noted further:

> 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.[92]

2.121 Service and workforce services shortages aside, covering the costs of mobility aids and devices, and processes for accessing government funding to assist with these costs, can also add to delays in getting support needed by people with LEOP/PPS. Dr Peel related her experiences of seeking financial assistance for mobility aids through the Queensland Government's Mobility Aids Subsidy Scheme (MASS)[93], telling participants:

> ... 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 ... I have another friend in Queensland with post-polio, and she has had to undertake the

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[90] Ms Elizabeth Telford, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 20.

[91] Ms Gillian Thomas, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 25.

[92] Mr Mark Booth, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 33.

[93] Queensland Government, http://www.health.qld.gov.au/mass/, viewed on 16 May 2012.

> 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.[94]

2.122 Similarly, Ms Telford emphasised the impact on LEOP/PPS sufferers caused by delays in accessing services and limited funding to assist with the costs of specialist equipment, telling participants:

> 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 [Polio Services Victoria] 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.[95]

2.123 Several references were made during discussion to the lack of financial assistance to help with other significant costs facing people with LEOP/PPS, including the capital costs associated with vehicle and home modifications.[96]

Committee comment

2.124 The Committee acknowledges that the specialist services provided by Polio Services Victoria are well regarded by health professionals and by people living with LEOP/PPS. However, the reality is that most people with LEOP/PPS in Australia do not have access to a specialist service, and instead must rely on generic health services. To ensure that these services are capable of addressing the specific needs of people with LEOP/PPS, as discussed earlier, the Committee concludes that raising awareness and education of health professionals is crucial.

2.125 The Committee is also confident that initiatives being implemented as part of the Australian Government's National Health Reforms will improve the capacity of these generic services to respond to the specific needs of people with LEOP/PPS. As already discussed, GP Super Clinics and

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[94] Dr Margaret Peel, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 24.

[95] Ms Elizabeth Telford, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 8.

[96] Ms Elizabeth Telford, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 25.

PCEHR will play a vital role in improving multidisciplinary care and better coordination of services for people with chronic conditions and complex care needs. There is also significant potential for the national network of Medicare Locals to contribute by addressing gaps in health services. The Committee understands each of the 62 Medicare Locals being set up will consult with local communities and health care professionals to build a profile of health care needs within the locality, to ensure that any deficiencies and gaps in services are identified and addressed.[97] The Committee also considers the possible role for Medicare Locals in raising awareness of LEOP/PPS and comments further in its conclusion at the end of the discussion paper.

2.126 The Committee is concerned that workforce shortages have also contributed to delays experienced by people with LEOP/PPS in accessing treatment or obtaining assistive aids and devices. The Committee understands that these shortages are indicative of a national shortage of health professionals in all fields, and reflects growing demand for services and an ageing population. However, the Committee is pleased to note that the Australian Government, through Health Workforce Australia (HWA), is actively pursuing workforce innovation and reform.[98] HWA's workforce innovation and reform program will develop health workforce planning models to support new models of health care delivery to meet emerging healthcare demands. Addressing workforce shortages across all health and allied health disciplines is a key element of this program.

2.127 Another issue of concern that clearly impacts not only on people with LEOP/PPS, but also on people with a disability more generally, is access to financial assistance to help meet the costs of disability. The Committee notes that during discussion references were made to state and territory government programs (eg MASS and SWEP) which provide subsidies for disability aids and equipment. While the provision of assistance for aids and equipment is largely the domain of state governments, the Committee realises that it may be difficult for individuals to identify potential sources of support that may be available to them. Therefore, the Committee believes that the development of a centralised web-based resource to provide accurate information on the financial support available for aids and equipment would be beneficial. Such a resource could be developed and supported by DoHA. Alternatively, this resource could be supported by the Australian Government Department of Families, Housing,

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[97] DoHA, http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/medilocals-lp-1, viewed on 16 May 2012.

[98] Health Workforce Australia (HWA), http://www.hwa.gov.au/, viewed on 24 May 2012.

Community Services and Indigenous Affairs (FaHCSIA) which has portfolio responsibility for progressing the Council of Australian Government's National Disability Strategy.[99]

2.128 In further considering services and supports for people with LEOP/PPS, the Committee notes the introduction of a National Disability Insurance Scheme (NDIS) which represents a fundamental and significant transformation to the way in which support is provided for people with disabilities in Australia. The basis of the NDIS is that it will deliver personalised care for people with significant and permanent disability.

2.129 In the 2012-13 Budget, the Australian Government committed $1 billion over four years for the first stage of the NDIS. The first stage will be trialled in up to four locations, and is expected to deliver personalised care and support for up to 10 000 people with significant and permanent disability from 2013-14 and expand to support up to 20 000 people from 2014-15.[100] The Committee is aware that some detail of the NDIS's implementation has still to be determined, including how the scheme will effectively operate in conjunction with supports available to people aged over 65 years through the aged care system. However, the Committee is confident that the NDIS will improve access to a range of services supports for significant numbers of Australians affected by disability.

Peer support and advocacy

2.130 Frequently during discussion, participants emphasised the importance of peer support for people with LEOP/PPS, as well as for their families and carers. Participants explained how many polio survivors, and families and carers benefited by being connected with others in similar situations, sharing experiences and information.[101] Polio Australia, the national peak body established in 2008 through collaboration of existing state post-polio networks, is the principle provider of peer support. Polio Australia assists polio survivors, and their families and carers, through nationally-focussed advocacy, the provision and dissemination of information and support for educational and networking activities to improve health and well-being.

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[99] Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), http://www.fahcsia.gov.au/sa/disability/progserv/govtint/nds_2010_2020/Pages/summary.aspx, viewed on 17 May 2012.

[100] Australian Government, http://www.budget.gov.au/2012-13/content/bp2/download/bp2_consolidated.pdf , viewed on 17 May 2012.

[101] Ms Gillian Thomas, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 5.

The state post-polio networks also continue to play a vital support role at local level.[102]

2.131 Summarising the kind of support provided by Polio Australia, Ms Thomas explained:

> 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.[103]

2.132 Since 2010, Polio Australia has also offered an annual self-management residentials to assist people with LEOP/PPS and their families and carers. According to Ms Thomas, the aim of the residentials is to help sufferers and their families to take a holistic approach to managing LEOP/PPS by focusing on body, mind and spirit.[104]

2.133 Although a small amount of funding has been available from state and territory governments to fund programs provided by some of the state-based post-polio networks[105], participants noted that by and large the supports provided by polio Australia and the state-based post-polio networks are funded by philanthropic donations. Polio Australia and the state-based networks are also heavily reliant on the contribution of the volunteer labour of their members and others to support their activities.[106]

Committee comment

2.134 As already acknowledged, the impact of LEOP/PPS is significant, not only for sufferers but also for their families and carers. The peer support and advocacy provided by Polio Australia and the state-based polio networks assists those affected by LEOP/PPS by providing access to information and advice, and also importantly by providing social and emotional supports.

2.135 The Committee was impressed by the commitment and passion of roundtable participants and their supporters, some of whom came to observe the day's proceedings. It was evident to the Committee that Polio

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[102] See footnote 63 for a list of state post-polio networks.

[103] Ms Gillian Thomas, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 5.

[104] Ms Mary-ann Liethof, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 18.

[105] See for example: Ms Gillian Thomas, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 30; Mr Brett Howard, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 33.

[106] Ms Gillian Thomas, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 4.

Australia and the state-based polio networks are a cohesive and unified group dedicated to improving the lives of polio survivors, their families and carers. As noted elsewhere in this discussion paper, DoHA's Chronic Disease Prevention and Service Improvement Flexible Fund may provide support to extend Polio Australia's peer support activities and the Committee encourages Polio Australia to investigate options of applying for funding under this initiative.

Research

2.136 Although not a key theme for discussion, on a number of occasions roundtable participants commented on the need of a high level of research across all aspects of LEOP/PPS. Research is needed to:

- establish the prevalence of LEOP/PPS in Australia and the scale of the population at risk;
- develop a clearer understanding of the pathophysiology;
- develop a diagnostic test;
- determine evidence-based best practice treatment and management; and
- assess the availability and suitability of health services.

2.137 While recognising the need for more research into LEOP/PPS in Australia, Dr Peel indicated that there are key centres of research in North America and Europe, noting:

> The research, as we have already indicated, might be inadequate [in Australia] 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.[107]

2.138 Roundtable participants spoke of efforts to try and quantify the number of polio survivors in Australia. Ms Liethof noted that there had been some research on prevalence of LEOP/PPS and population at risk conducted by

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[107] Dr Margaret Peel, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 7.

the Australian National University's National Centre for Epidemiology and Population Health.[108] Ms Thomas also referred to data collected as part of Polio Australia's Polio Register.[109]

2.139 Ms Thomas also reinforced the need for more work to establish evidence-based best practice for treatment and management, noting:

> 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 ... High-quality research into the effectiveness of pharmacological and rehabilitation interventions are needed ... 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.[110]

Committee comment

2.140 Although there is some research on LEOP/PPS being conducted at various locations internationally, the Committee considers that there is scope to extend this research, particularly in Australia. The National Health and Medical Research Council (NHMRC) is the primary source of funding for biomedical research in Australia. In 2011 the NHMRC provided funding for research amounting to almost $755 million. This research funded diverse projects under a number of broad research areas including basic science, clinical medicine and science, public health and health services research.[111]

2.141 However, a search for the term 'polio' in the NHMRC research funding dataset for 2002-11 did not identify any LEOP/PPS research projects funded over the last decade. The Committee is unable to determine whether this is because no applications for LEOP/PPS research were submitted for funding over this period, or whether LEOP/PPS research applications were submitted but did not progress to funding through the competitive peer review process.[112]

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[108] Ms Mary-ann Liethof, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 6.

[109] Ms Gillian Thomas, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 5.

[110] Ms Gillian Thomas, *Official Committee Hansard*, Melbourne, 30 March 2012, p. 4.

[111] National Health and Medical Research Council (NHMRC), http://www.nhmrc.gov.au/grants/research-funding-statistics-and-data/funding-datasets, viewed on 17 May 2012.

[112] Note data which indicates that approximately 1 in 4 project grant applications are successful.

2.142 The Committee notes that the NHMRC's Strategic Plan 2010-12 (the Strategic Plan) lists the following major health issues that will be the subject of special consideration by the NHMRC:

- building a self-improving health system;
- Indigenous health and well-being;
- ageing and health;
- chronic disease;
- mental health;
- genomic medicine and frontier technologies;
- planning for emerging infectious disease threats;
- examining alternative therapy claims;
- global health; and
- health consequences of climate change.[113]

2.143 The Strategic Plan also confirms the NHMRC's commitment to continue to support research relating to National Health Priorities which include musculoskeletal diseases, chronic respiratory diseases, injury and mental health.[114] Given the relevance of many of the NHMRC's research priorities to aspects of LEOP/PPS that are currently poorly understood, the Committee concludes that there are opportunities for high-quality, research on LEOP/PPS to be conducted in Australia.

2.144 The Committee also understands that Australia's research community is world class and well-regarded internationally. The Committee suggests that Polio Australia, through its Clinical Advisory Group, seek to engage with the research community to encourage those with relevant expertise to seek NHMRC funding (or alternative funding available, for example through DoHA's Chronic Disease Prevention and Service Improvement Flexible Fund or from philanthropic sources) to support research into LEOP/PPS.

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[113] NHMRC, 2010-12 Strategic Plan; http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/nh132_strat_plan_2010_2012.pdf, viewed on 17 May 2012.

[114] NHMRC, 2010-12 Strategic Plan; http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/nh132_strat_plan_2010_2012.pdf, viewed on 17 May 2012.

Committee conclusion

2.145 The Committee understands that LEOP/PPS and its impact on the lives of sufferers, their families and carers have gone largely unrecognised in Australia. Therefore, when the Committee decided to hold a roundtable to learn more about the condition, an important aim was to raise the profile of LEOP/PPS through open discussion in a public forum. To support its aim, in addition to invited roundtable participants, observers were also encouraged to attend the day's proceedings. The Committee was therefore pleased to see that a sizeable contingent of observers attended proceedings, many staying for the entire day and lending their support to participants. For those who were unable to attend proceedings in person, proceedings were live webcast through the Parliament of Australia website. In the week following the roundtable, a transcript of proceedings was published on the Parliament of Australia website.[115]

2.146 To support its aim of raising the profile of LEOP/PPS further, the Committee undertook to produce this discussion paper for presentation in Parliament and to the Minister for Health for consideration. Importantly, this discussion paper not only outlines the key issues raised during discussion, but at various points the Committee has clearly expressed its views in Committee comment. However, and while acknowledging the limits of inquiry conducted by a single roundtable, on further consideration the Committee concluded that some key issues warrant specific recommendation. In particular, the Committee considered recommendations should address that the need to determine the potential size of the population at risk of developing LEOP/PPS and options for raising awareness.

2.147 The Committee was particularly concerned about the lack of information on the prevalence of LEOP/PPS and the size of the population at risk. While the Committee understands that basic research is needed to improve diagnostic capability which will enable accurate determination of prevalence, the Committee considers in the meantime that there is still a crucial need to establish a mechanism to gauge the possible extent of LEOP/PPS in Australia and the population at risk. As noted earlier, the Committee is aware that the ABS conducts a number surveys which examine the health of Australians, and assess levels and severity of disability. The Committee recommends that the ABS include questions to

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[115] Parliament of Australia; http://www.aph.gov.au/Parliamentary_Business/Committees/House_of_Representatives_Committees?url=haa/leop%20pps/index.htm

estimate the number of polio survivors living in Australia and determine within that population the proportion currently experiencing post-polio sequelae. The Committee has not specified which of the ABS surveys should be used, on the understanding the ABS itself is best placed to make this determination. The Committee also acknowledges the key role of Australian Institute of Health and Welfare in collecting, analysing and disseminating health and welfare related data and statistics.

Recommendation 1

The Committee recommends that the Australian Bureau of Statistics and/or the Australian Institute of Health and Welfare establish mechanisms through inclusion of appropriate questions in existing health and/or disability surveys to estimate and report on the size of the population of polio survivors living in Australia, and the proportion of that population experiencing the late effects of polio/post-polio syndrome.

2.148 The need to increase awareness and improve understanding of LEOP/PPS is clearly a significant issue. In the absence of a definitive diagnostic test, the Committee understands that poor awareness of LEOP/PPS among GPs and other health professionals can contribute to delays in diagnosis. As noted earlier this results in frustration for LEOP/PPS sufferers as they wait to receive a diagnosis, and in some cases inappropriate treatment which can be detrimental for affected individuals.

2.149 The Committee understands that there are diverse models for teaching medical students and students of the other health professions in Australia. Responsibility for the content of curricula lies primarily with the medical educators and health profession training providers, within a broad framework set by the relevant health profession National Board.[116] The Committee is concerned that components of various medical and health professional curricula that deal with chronic conditions, diagnostic reasoning, and patient treatment and management may overlook

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[116] In 2009-10 Australian states and territories enacted legislation to establish a national registration and accreditation scheme (NRAS). The NRAS establishes a series of National Boards which set standards, codes and guidelines for regulated health professions. National Boards regulate the following health professions: medicine, nursing and midwifery, pharmacy, physiotherapy, psychology, osteopathy, chiropractic, optometry, dental and podiatry.

LEOP/PPS, particularly as polio is now generally considered to be of historical relevance only in Australia. The Committee is keen to ensure that curricula for medical students, and where relevant for students of other health professions, include information on LEOP/PPS to raise awareness of the condition as a possible diagnostic outcome and of best practice for treatment and management.

Recommendation 2

The Committee recommends that the relevant National Boards, in consultation with key stakeholders including peak professional bodies, medical/health educators and training providers, seek to ensure curricula for students includes information on the late effects of polio/post-polio syndrome, to raise awareness of the condition as a possible diagnostic outcome and of best practice for treatment and management.

2.150 The Committee has already noted that alternative mechanisms will need to be used to raise awareness of LEOP/PPS among health professionals who are already in practice and to inform the community. The Committee has identified the potential for activities supported under Australian Government reforms to primary health care to provide additional opportunities for dissemination of information on LEOP/PPS and for education. Specifically the Committee considers that Medicare Locals could have a key role in raising awareness of LEOP/PPS.

2.151 The Committee notes that as part of their remit, Medicare Locals have an important role in developing linkages with state and territory government departments of health. Governance arrangements for Medicare Locals provide for ongoing community engagement and input with regard to addressing local health needs and priorities.

Recommendation 3

The Committee recommends that Medicare Locals actively engage with Polio Australia and the state-based post-polio associations, with state and territory government departments of health, and with general practitioners to promote activities which will raise awareness of the late effects of polio/post-polio syndrome:

- **among practicing health professionals through continuing professional development; and**
- **in the community through patient education, noting the need to tailor communication to enhance engagement with specific population groups taking into account demographic factors such age as and cultural background.**

Steve Georganas MP
Committee Chair

26 June 2012