SMASAC Working Group

Post Polio Syndrome/
Late Effects of Polio
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Introduction

The reduction of polio in the last 50 years, and its eradication from large parts of the world, has been one of the great triumphs of immunisation policies. It was formerly a greatly feared disease causing death or substantial disability in previously healthy, often young, individuals. The period between 1947 and the early 1960s saw a series of epidemics in which between 3,000 and 7,000 cases were reported in the UK. The introduction of the Salk polio vaccine in 1956 and the Sabin vaccine in 1962 produced a dramatic change in the UK and elsewhere. Since 1962, less than 100 cases have been reported per year, and the last “natural” case of polio in the UK was in 1982. Only very occasional cases have been reported since then, which have been imported cases, vaccine induced cases or similar syndromes caused by other viruses. In 2002 there were less than 2000 new cases worldwide, and Europe. The Americas and the Western Pacific regions are certified polio free. Eradication of polio infection from the whole world within a few years is a feasible goal.

Why then is this report necessary in Scotland in 2010? A substantial number of people who were affected as children during the polio epidemics in the middle of the last century are still alive. The youngest of them will only be in their early 50s. In recovery from the acute attack, individuals were encouraged to get on with their lives using aids as required. This bred an admirably independent attitude in the “polios” or “survivors” as many refer to themselves. As they have aged, many years of abnormal gait or weight bearing have taken their toll, often added to by effects of aging itself. Thus, those experiencing these late effects of polio (LEOP) have found their needs for services and aids increasing. Accepting these needs conflicts with the independence so many have fought to maintain over the decades.

In addition, Post Polio Syndrome (PPS) has in recent years been recognised as a distinct clinical condition which now has agreed diagnostic criteria. In this still incompletely understood condition, individuals who had suffered polio develop new neurological difficulties which cannot be explained on the basis of the effects
of the acute attack, aging or another disease. Typically, the features develop 20 to 40 years after the acute attack. Mobility problems are most common but other features, such as respiratory difficulties may also occur. Many of these issues are covered fully in a very helpful review which appeared after the Working Group completed its work.3

The Scottish Post Polio Network (SPPN) has campaigned since 2001 for greater recognition of the needs of individuals with new or continuing problems due to polio. Following their representations to Scottish Ministers, the Scottish Medical and Scientific Advisory Committee set up a Working Group in 2008 to consider the issues. The current report is the result.

The main messages from the report are:

- There is still a significant number of individuals in Scotland affected by PPS/LEOP who will require services for up to another 40 years.
- Many of the difficulties faced by PPS/LEOP individuals are the same as for individuals with other chronic neurological conditions.
- PPS is a diagnosis of exclusion and other possible causes of the new features must be excluded before it can be accepted.
- Many healthcare professionals who will encounter individuals with PPS have, understandably, little or no knowledge of this newly recognised and relatively rare condition. Even many polio survivors are unaware of PPS.
- Services are patchy and poorly coordinated.

With these findings we have recognised the importance of empowering the individual who has suffered from polio by making them more aware of PPS/LEOP and of encouraging them to use services to which they can self refer. The Report indicates how health and social care organisations, including those in the voluntary sector, can carry such activities forward. We have also considered possible models of how the development and coordination of services might be tackled. The work carried out in considering these options will also provide a
good template for considering how individuals with other long term neurological conditions might be supported.

Chairing the PPS/LEOP Working Group has been an enjoyable and productive experience. The members of the Working Group contributed generously of their time and their expertise in a collaborative spirit. Particular mention must be made of the members of SPPN who served on the Working Group. Without their willingness to share their personal experiences, and those of their fellow members, the Working Group would not have been able to gain such a detailed insight into the key issues. I am most grateful to all members of the Working Group and to the staff of the Scottish Government Health Directorates (SGHD) who so ably supported it.

Prof Jim McKillop
April 2010

1. NHS Website http://www.immunisation.nhs.uk/Vaccines/DTaP_IPV_Hib/The_diseases/Polio accessed 6th April 2010


Executive Summary

Background
It is some 50 years since the last epidemic of acute poliomyelitis in Scotland, but significant numbers of polio survivors still experience the after effects of the illness. In some this has been aggravated by the effects of aging and/or the development of the recently recognised PPS. Following representations from the Scottish Post Polio Network (SPPN), the Scottish Medical and Scientific Advisory Committee (SMASAC) set up a Working Group with the following remit:

To report to the Scottish Medical and Scientific Advisory Committee (SMASAC) on the following issues relating to PPS and LEOP:

- Defining the condition;

- Determining its prevalence in Scotland;

- Raising awareness of the condition, especially in primary care, through adaptation for Scotland of existing guidance; and

- Considering the potential benefits of a Managed Clinical Network approach to the provision of services.

The Working Group consisted of polio survivors and a range of healthcare professionals. It met on seven occasions between November 2008 and February 2010, taking oral and written evidence from a variety of individuals and organisations. Secretariat support was provided by SGHD.

Section 1
This considers the definition of PPS and of the LEOP. It indicates why the working party felt it was important to consider both of these conditions. Work by the Scottish Public Health Network, on behalf of the Working Group, noted the difficulties of obtaining a precise estimate of PPS/LEOP in Scotland. From that
work and from information in the literature, an estimated prevalence of between 1,000 and 6,000 cases in Scotland was determined. This section also notes the substantial lack of awareness of PPS among healthcare professionals and even polio survivors. Finally, the section places PPS/LEOP in a broader policy context, using it as an exemplar of chronic neurological conditions.

**Section 2**
In this section, the diagnosis and management of PPS/LEOP are considered. Attention is drawn to key documents such as the Queensland Health Review on the Late Effects of Polio and the recent British Polio Fellowship (BPF) booklet on PPS. The key message is the importance of treating PPS as a diagnosis of exclusion and of always excluding other possible causes for the patient’s new clinical feature(s). Advice is given on the management of various aspects of PPS/LEOP, including sleep and respiratory problems, exercise, orthotic needs, wheelchair services and lymphoedema. The importance of multi-professional services is stressed as is the need to consider both medical and social needs.

**Section 3**
This consists of a review of current and possible future service models for PPS/LEOP, ranging from the status quo to establishing a national specialist centre. The patchy and unsatisfactory nature of current services is noted. The possibility of patient-self referral into some services is noted.

**Section 4**
This section considers the important role the voluntary sector has in informing and supporting those with PPS/LEOP. In particular, the work of SPPN, BPF and Disabled Living Centres is highlighted.

**Section 5**
In this section the following recommendations are made:

- The definition of PPS set out in the National Institute for Neurological Disorders and Stroke (NINDS) criteria should be accepted.
• Individuals with possible PPS should be referred to a neurology centre for evaluation.
• Those with respiratory features should be referred to a respiratory centre for assessment, including sleep studies where indicated.
• A prevalence of 1,000 to 6,000 should be accepted for Scotland. The Working Group does not believe that further epidemiological work in this area is justified.
• It is necessary to raise awareness of PPS amongst health professionals and polio survivors. The Working Group recommends that the BPF booklet on PPS and the Queensland Review should be made widely available to polio survivors and to health professionals in NHSScotland. The Group also recommends that SGHD considers how the NHS Direct Map of Medicine pathway for PPS could be made available to NHSScotland. Information on self-referral policies and processes for community nursing, occupational therapy and physiotherapy services should be collated and made available via the SPPN website.
• NHS Quality Improvement Scotland (NHS QIS) should be asked to consider the development of Best Practice Guidelines for the treatment of PPS/LEOP for physiotherapists and orthotic service providers.
• SGHD should ensure that the needs of those with PPS/LEOP are kept in mind during the process of implementing the NHS QIS clinical standards for neurological health services. The Regional Planning Groups should be asked to consider establishing a MCN for PPS/LEOP alone or in conjunction with other conditions where patients have similar needs.

The Report ends with a list of key references and a number of appendices which explore in greater detail some of the topics considered in the main body of the Report.
Section 1- Background and prevalence

1.1 Criteria and definitions

There are agreed clinical criteria for a diagnosis of PPS such as the National Institute for Neurological Disorders and Stroke (NINDS) criteria (detailed at Annex A). In addition, a considerable number of polio survivors will experience new symptoms, related to their childhood polio, without fulfilling the diagnostic criteria for PPS. These people may more accurately be described as experiencing the late effects of polio (LEOP). Early in its discussions, the group felt that to focus exclusively on patients with a formal diagnosis of PPS when considering the issues of awareness raising and service provision would disadvantage those polio survivors who do not have a diagnosis of PPS but are experiencing similar problems. This report will therefore consider both PPS as clinically defined and LEOP.

At its first meeting, the group considered and accepted the following remit: “To report to the Scottish Medical and Scientific Advisory Committee (SMASAC) on the following issues relating to post-polio syndrome and late effects of polio:

• Defining the condition;

• Determining its prevalence in Scotland;

• Raising awareness of the condition, especially in primary care, through adaptation for Scotland of existing guidance; and

• Considering the potential benefits of a Managed Clinical Network approach to the provision of services.”

1.2 Symptoms

The symptoms experienced by people with PPS and LEOP vary considerably in their range and severity. Commonly, new muscle weakness, fatigue and pain are reported, and in some cases respiratory problems may develop or worsen. New and/or worsening disability will require review of the individual’s need for orthotic, physiotherapy and occupational therapy services, as well as consideration of walking aids or wheelchair use. Reduced mobility is likely to
affect independence. Psychological difficulties related to this unexpected change in personal circumstances are common. PPS commonly develops 2-4 decades after the episode of acute poliomyelitis, and as the last major epidemic of polio in Scotland was in the late 1950s, most affected individuals are now aged 50+. Since acute polio is now exceptionally rare, post polio problems are self-limiting in terms of overall prevalence (barring rare new cases and immigration), but are not a short-term concern. Support for individuals affected by PPS or LEOP will be required over the next 40 years.

### 1.3 Prevalence

An accurate estimate of the prevalence of PPS is exceptionally difficult for a number of reasons. Firstly, case definition is complicated by the spectrum of residual weakness experienced by people with PPS and by the number and complexity of presenting co-morbidities. The variability in reported estimates of PPS prevalence derived from research studies described in Annex B is clear evidence of these difficulties in case definition. Secondly, there is a

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What are the symptoms of PPS?
(adapted from ‘Post Polio Syndrome: A practical guide to understanding and living with the condition’ © The British Polio Fellowship 2009)

- **Weakness**: New or increasing weakness is often the most easily recognisable symptom of PPS
- **Muscle fatigue**: This is common in PPS
- **General fatigue**: An overwhelming feeling of exhaustion, weakness and sometimes mental fatigue
- **Muscle pain**: This is very common in people with PPS and is usually described as aching, especially after activity
- **Joint pain**: Weakness and injury around joints can also lead to pain due to compressed (pinched) nerves
- **Muscle loss**: People with PPS may experience loss of muscle bulk
- **Sleep disturbance**: Sleep disturbances can be common
- **Breathing problems, problems with swallowing, cold intolerance**
general lack of awareness among polio survivors themselves about PPS, meaning that many people will not have made themselves known to NHS services. Recognising that a reasonably reliable estimate would be required for planning purposes, the Scottish Public Health Network was asked to provide guidance to the group on the potential for further work in establishing prevalence. The Network’s report is included at Annex C. It concluded that the benefit to be gained from a more precise estimate was unlikely to justify the time and expense which would be necessary to design a surveillance method to overcome the difficulties outlined above. For the purposes of this report, therefore, the number of individuals in Scotland who may be affected by PPS is accepted as between 1,000 and 6,000.

1.4 Awareness and understanding

As a relatively recently defined clinical diagnosis, PPS has historically been under-recognised by the medical and healthcare professions. Personal testimonies and anecdotal evidence from polio survivors confirm that there have been difficulties in accessing appropriate treatment, which has depended to a great extent on whether the individual’s GP had knowledge and understanding of PPS/LEOP, and of appropriate onward referral. Acceptance and understanding of PPS/LEOP has improved in recent years, but not in a consistent or coordinated manner. Patients may continue to experience varying levels of knowledge of PPS/LEOP among the healthcare professionals they deal with. This is likely to be a particular issue at GP/community care level, partly since the number of polio survivors any individual GP will have registered to their practice is very small. Similarly, district nursing, occupational therapy (OT) and physiotherapy allied health professionals (AHPs) will encounter polio survivors among their caseload only infrequently. Once appropriately referred, however, the patient is more likely to be treated by a consultant with knowledge of PPS/LEOP.

1.5 Polio survivors’ awareness

Knowledge among polio survivors themselves was also felt to be poor. A recent publicity campaign organised by the SPPN, with SGHD funding, which
featured case studies of polio survivors and encouraged those with new symptoms to contact the SPPN, confirmed this. Among the responses received, some common themes emerged including: no prior awareness of PPS, expressions of relief to hear of other polio survivors experiencing symptoms, a tendency to blame deteriorating physical function or fatigue on ageing only, difficulties in accessing treatment and having symptoms ‘taken seriously’. There is a clear respondent bias in this sample, since polio survivors who are aware of PPS/LEOP and receiving appropriate treatment are less likely to have responded to the campaign. However, of the estimated 1,000 to 6,000 polio survivors in Scotland likely to be experiencing PPS at some level, only 500 are known to the SPPN and/or the British Polio Fellowship (BPF).

1.6 Policy Context

PPS/LEOP is an exemplar of both a long term condition and a neurological condition. In keeping with the generic work which SGHD is undertaking on long term conditions, this report draws on the experience of people living with PPS/LEOP in order to promote improvements in service provision. These services will also benefit from the development of the Scottish Government’s Quality Strategy, which not only emphasises the value of people’s stories but which will also have self management of long term conditions at its heart.

As a neurological condition, PPS/LEOP will also form part of the work which NHS Quality Improvement Scotland (which is replaced Healthcare Improvement Scotland from 1 April 2011) currently has in hand to implement the clinical standards for neurological health services that it launched in January 2010. Central to that process is working with key stakeholders to build a culture of improvement that will result in measurable improvements in neurological services for patients in Scotland. The group is keen that those living with PPS/LEOP should benefit from those improvements.
Section 2 - Diagnosis and management

2.1 Diagnostic approaches

There is no specific diagnostic test for post polio syndrome and some clinicians still contest whether it is a specific diagnosis. It is a diagnosis of exclusion. In considering a diagnosis of PPS or in attributing symptoms to the late effects of polio in someone presenting with a possible history of polio, the group suggests an approach based on the following initial questions:

- Did the individual have polio?
- Are their new clinical problems due to a different disease?
- If the patient appears to be have PPS/LEOP, are the symptoms mechanical or due to new neurological deterioration?

**Did the individual have polio?**

It may seem strange to ask whether someone who has been told for years they had polio ever had the condition, but this question cannot always be answered with certainty. A number of studies have quoted figures of between 5 and 15% of patients presenting to post-polio clinics whose belief that they had polio could not be substantiated \(^1,^2,^3\). There is often little clarity about the recall of the original illness and old medical records may be unobtainable. In addition, some cases of polio had few symptoms. The likelihood that the individual had polio can be assessed by asking about when the illness took place; where the patient was treated (certain hospitals were more likely to take polio cases); the length of time the person was in hospital; any procedures that were undertaken (e.g. plaster beds, tendon operations, respiratory support), the pattern of the illness up to when the most severe disability was and what the patient was like at discharge. It is also important to remember that some cases never reached hospital and thus the above questions will not always be relevant.

This should be followed by clinical examination to establish whether the features now are typical of previous polio. However, confirming the
presence of features of previous polio does not exclude the possibility that the patient’s current problems are due to other conditions which have developed.

**Are the new clinical problems due to a different disease?**

Much of the post polio diagnosis has to be a diagnosis of exclusion, and even once previous polio has been established it cannot be assumed that new symptoms are due to PPS. Warning signs might be abnormal sensation (either reported as a symptom or found on examination), new upper motor neurone signs or rapidity of onset. It is essential that other causes for the patient’s symptoms and signs, particularly those which are remediable, are assessed and excluded.

<table>
<thead>
<tr>
<th>The following features are compatible with PPS/LEOP, though other causes must also be considered:</th>
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<tbody>
<tr>
<td>• Breathlessness</td>
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<tr>
<td>• Fatigue</td>
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<tr>
<td>• Sleep disturbance or orthopnoea</td>
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<tr>
<td>• Weakness/wasting in any territory</td>
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<tr>
<td>• Pain</td>
</tr>
<tr>
<td>• Falls or fracture</td>
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<tr>
<td>• Dysphagia</td>
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<table>
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<tr>
<th>The following features are very unlikely to be due to PPS/LEOP:</th>
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<tr>
<td>• New sensory change (except entrapment neuropathy in LEOP)</td>
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<tr>
<td>• Bladder disturbance*</td>
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<tr>
<td>• Upper motor neurone signs</td>
</tr>
<tr>
<td>• Change in personality or dementia</td>
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<tr>
<td>• Involuntary movements</td>
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*Bladder disturbance has been described as being due to PPS/LEOP but is much more likely to be due to other causes.
If the patient appears to have PPS/LEOP, are the symptoms mechanical or due to new neurological deterioration?

If the symptoms do appear to be due to a polio related process, there is then a need to differentiate mechanical issues from new neurological weakness. This is done initially by history and examination. On examination, the patient’s gait, their limb length, their back, range of movement in the joints and muscle weakness must all be assessed. Nerve entrapments (more common in post polio patients) should be excluded.

Degenerative joint changes may occur either in the affected limb or in unaffected limbs which have been compensating for weakness elsewhere. If the patient has pain, neurogenic pain must be differentiated from locally determined nocioceptive pain. Orthopaedic procedures, such as joint replacement, or other interventions should be considered for mechanical problems.

Attribution of new weakness to PPS/LEOP can be difficult when it is in a part of the body previously affected in the acute attack. Sometimes patients manage until they reach a critical threshold in muscles which have been affected mildly or subclinically in the acute attack such that they cannot function any longer. PPS/LEOP should be considered only after excluding other causes for changing patterns of weakness, deterioration in muscle or physical function or decreasing muscle mass. Very few patients with post polio will be young adults and muscle bulk diminishes with increasing age. There is often considerable difficulty in determining how much new muscle weakness is due to PPS/LEOP rather than other diseases, disuse or age related decline in muscle function. The measures taken to exclude other disease may be helpful in deciding that there is a new process going on rather than simple age-related deterioration.
2.2 Assessment and Management of individuals with PPS/LEOP

It is essential that the assessment and the management of individuals diagnosed as having PPS or LEOP consider their needs across medical and social care boundaries. Some of the solutions will be deliverable by healthcare professionals only and some by social care only, but a significant number of individuals will require input from both groups. Thus individuals with post polio problems potentially will require a wide range of services. For a number of these services, the individual can self-refer or can go through routes other than their GP. There is a challenge in making individuals more aware of these alternative routes to services.

2.3 Exercise and PPS/LEOP

A wide variety of authors recommend measures that conserve energy, for example by aids and appliances and by alterations of lifestyle, but advice on exercise in post polio has varied.

A seminal paper by Maynard¹ suggested that active exercise could aggravate pain problems and that no attempt should be made to strengthen muscles which were weakened in normal function. Subsequent papers⁴,⁵ supported the concepts that one should ‘go for help’ rather than exercise and of ‘conserve it to preserve it’.

The UpToDate website states that the greater the degree of recovery from acute polio the more likely is later post polio syndrome – suggesting a failure of compensatory mechanisms that facilitated the initial recovery. This suggests excessive exercise or overuse could predispose to new weakness.

However, since the late 1980s there has been evidence suggesting that tailored exercise regimes might be beneficial ³,⁶,⁷,⁸,⁹,¹⁰,¹¹. Thus, there is confusion in the literature. However, the European Federation of Neurological Societies (EFNS) guideline on management of post polio
syndrome\textsuperscript{12} recommended that both isokinetic (muscle contraction with shortening) and isometric (muscle contraction without shortening) supervised aerobic muscular training were safe and effective in preventing further decline from moderate weakness. It also stated that muscular training could improve muscular fatigue, weakness and pain. Training in a warm climate and non-swimming water exercises were particularly useful. Respiratory muscle training was said to improve pulmonary ventilation.

The Queensland Review highlights the possible benefits of hydrotherapy.\textsuperscript{14}

2.3a Evidence based approaches

Based on these studies and recommendations, the group suggests the following approaches:

- **Muscles weakened because of previous polio**
  Exercising these muscles should be at intensities and for durations below those which cause fatigue and should be encouraged particularly for muscles which are crucial for a particular function, such as stabilising the hip to permit better gait or improving shoulder strength to permit use of an arm where the distal muscles are still good. Although isometric exercise has been found to be safe in the EFNS guidelines, other papers caution against this. Where isokinetic exercise can achieve the same aims, there is less evidence to suggest this is harmful. Muscles that are already demonstrating pain on everyday movement should be the subject of particular caution.

- **Muscles weakened by disuse**
  There seems to be no convincing evidence against exercise in muscles weakened by disuse. Exercise of these muscles would be reasonable. There may sometimes be difficulty in differentiating between those which are primarily weakened by disuse and those weakened by polio particularly as detailed neurophysiological testing in post polio often reveals evidence of previous polio involvement in muscles previously thought to have been unaffected.
• **General exercise and fitness**

There is sufficient evidence for the beneficial effects of aerobic and cardiovascular fitness exercise to recommend this firmly to all patients who are not limited by cardiorespiratory disease. In addition, exercise to maintain muscle length and joint range (flexibility) and balance can be recommended universally, particularly when non-fatiguing and not aimed at muscle strengthening.

### 2.4 Wheelchair use in PPS/LEOP

Two problems cause particular concern in post polio: the need to begin using a wheelchair after many years of independent mobility; and transition from manual occupant-propulsion to a powered wheelchair.

In the first of these, the concern arises in the determination of people who have had polio to retain independence. Polio survivors will have been encouraged during their acute illness to do all that they can to live a ‘normal life’, often with great success over many years. Against this background transition to using a wheelchair or other additional mobility aids may be seen as a defeat and be difficult psychologically. The psychological effects may require professional support. However, wheelchair mobility in many cases needs less energy than walking, especially walking with a grossly impaired gait. Wheelchair use can also spare the strain on joints in the legs (although there can be demands on upper-limb joints). Thus with advancing muscle weakness, joint degeneration, or declining exercise tolerance, transition to wheelchair use can be a positive move, allowing more social activity. A further issue is people who fall frequently, for whom a wheelchair can be much safer. However, health professionals advising such a change need to be sensitive to the anxieties that someone with polio may experience at this point.

As post polio progresses, however, manual occupant-propulsion can give rise to its own problems. Weakness and poorer exercise tolerance may make
manual propulsion hard, especially when the weakness is in arm or trunk muscles. In these circumstances, some authorities believe muscle weakness could be accelerated by manual propulsion. Joints in the arm (especially the shoulder) can become painful, and arthritic conditions can deteriorate. Powered wheelchairs may then become necessary.

Relatively recently, some accessories have become available to give power assistance to a manual wheelchair. These can reduce some of the strain of propulsion but do not have the performance and range of a full powered wheelchair. There is a wide and bewildering variety of designs available to meet the wide range of individual mobility requirements. These extend from small compact designs intended for use only indoors, to large complex high performance (and expensive) designs intended to tackle outdoor environments. Powered wheelchairs can also have additional powered features, such as seat tilt or recline, or elevating leg rests. More complex designs may have powered elevating seats to allow access to high tables or shelves. These features may allow longer tolerance of the sitting position or increase independence. If the user cannot manage a standard joystick hand control, a variety of special controls can be fitted, though these are rarely successful in outdoor environments.

In addition the use of scooters has become popular for people who can walk indoors but require power assistance with outdoor mobility.

▶ It is strongly recommended that people seek professional advice in selecting the optimum wheelchair. This can be obtained from NHS, Local Authority advice centres, or accredited dealers.

Wheelchair users then need to consider how they can obtain the required wheelchair. Sources may be statutory (NHS), charitable or private. NHS provision of powered wheelchairs has to date been limited to those unable to walk or propel themselves indoors manually. Post polio survivors have reported feeling disadvantaged by this, as they may be able to walk short
distances, but fatigue rapidly and some are concerned that continued occupant-propulsion can be harmful. In fact, NHS powered wheelchair prescription is possible if it is medically inadvisable for the individual to manually propel themselves. The conditions for NHS provision in Scotland are currently under review. In addition equipment to preserve employment, including powered wheelchairs where appropriate, can sometimes be funded by the Department of Work and Pensions ‘Access to Work’ scheme. Some charities may also provide help with the purchase of powered wheelchairs.

Wheelchairs can have a major effect in assisting the post polio survivor to prolong their independent mobility, but need careful selection to ensure the appropriate wheelchair is chosen.

It should be recognised that other forms of assistive technologies may be of value to polio survivors (see Annex G).

2.5 Respiratory and sleep services

There is general agreement concerning the nature of the potential respiratory aspects of PPS and LEOP. These can be divided into three broad groups:

- **Sleep disorders** – obstructive sleep apnoea, central sleep apnoea, nocturnal hypoventilation, sleep related abnormal muscle movements, sleep disruption due to musculoskeletal discomfort.
- **Respiratory insufficiency** – hypercapnic respiratory failure due to respiratory muscle weakness and chest wall distortion.
- **Impaired sputum clearance** – weak cough and poor protection of upper airway.

The questions which arise are:

- Frequency of each type of respiratory problem.
- Relevance of respiratory symptoms to a diagnosis of PPS/LEOP.
- Predicting the pace and pattern of progression.
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- Success of interventions.
- Appropriate infrastructure of respiratory care.

2.5a Frequency of respiratory problems
As with other post polio symptoms, there is a wide range reported in the literature for respiratory symptoms. Farbu et al\(^{13}\), in a series of 85 patients found 20% had some impairment of peak expiratory flow, but only 2% had dyspnoea. The Queensland Review\(^{14}\) reported new breathing difficulties in 39% of subjects. An EFNS task force review\(^{12}\) concluded that whilst shortness of breath was a common symptom, respiratory function was often normal and symptoms could be explained by cardiovascular deconditioning and weight gain.

2.5b Sleep problems and PPS/LEOP
The incidence of sleep problems related to PPS/LEOP is similarly difficult to estimate but all reviews indicate a number of reasons why sleep problems might be commonly encountered:

- Obstructive sleep apnoea – imposed sedentary lifestyle with weight gain, bulbar weakness.
- Central sleep apnoea – residual dysfunction of bulbar reticular neurons.
- Abnormal muscle movements – periodic leg movement in sleep [PLMS].
- Musculoskeletal discomfort causing sleep fragmentation.

2.5c Relevance of respiratory symptoms to a diagnosis of PPS/LEOP
No respiratory symptoms described in literature are specific to PPS/LEOP. Respiratory involvement is indicated from the overall clinical picture with ‘alerts’ being:
Risk factors: initial respiratory problems, late age of acute polio and possibly very good recovery pattern. Significant kyphoscoliosis, suspicion of bulbar involvement.

Sleep aspects: disrupted sleep in conjunction with daytime hypersomnolence (elevated Epworth score) and poor concentration. Worsening snoring.

Hypoventilation: new orthopnoea, and/or morning headache, ankle swelling.

Respiratory muscles: dyspnoea on exertion or rest without obvious cardiorespiratory cause.

Expiratory muscles/bulbar: poor clearance of bronchial secretions and/or repeated chest infections.

(Adapted from Queensland Review) 14

Very rapid onset of respiratory muscle weakness causing respiratory failure is conceivable as a first clinical presentation but other muscle involvement is inevitably present and expert neurology assessment would be required for confirmation. The presence of any of the alerts above should lead a neurologist to consider a respiratory assessment.

Any of the following should alert respiratory physicians to consider PPS/LEOP:

- History of polio.
- Mixed sleep problems especially if there is a component of central sleep apnoea or a poor response to initial therapy.
- Unexplained weak cough or aspiration pneumonia.
- Lower limb weakness in patients with chest bellows impairment.
2.5d Predicting pace and progression – relevant tests

There is general agreement that the more severe the respiratory involvement during acute poliomyelitis, and the older when affected, the likelier are late respiratory difficulties.

Evidence about respiratory testing is garnered from case series and large centre experience. There appears to be no convincing evidence of any more rapid lung function decline in post polio populations than normal. Midgren\textsuperscript{15}, the EFNS review\textsuperscript{12} and data from the Lane Fox Unit\textsuperscript{16} have all suggested that sleep studies could more sensitively identify patients who are likely to require intervention than standard lung function tests.

Based on these data, the group suggests the following approach in post polio patients with respiratory symptoms:

► As in any respiratory problem, a measurement of vital capacity (VC) and an arterial blood gas sample [if oxygen saturation <95%] are important.

• If these are normal, this is reassuring and there is no real evidence for further or serial testing unless symptoms or signs deteriorate.
• If they are significantly impaired [55 – 70 % predicted] and no clear cause is identified, additional respiratory muscle tests should be performed.
• If there is evidence of respiratory muscle impairment an annual VC is indicated.

► If the initial VC is less than <55%, a sleep study should be performed. If this is abnormal and the individual has relevant symptoms there should be a low threshold for nocturnal non invasive ventilation (NIV).

► If the initial PaCO2 elevated, full pulmonary function testing and an active approach to NIV are indicated.


2.5e Success of interventions

There is good evidence that respiratory insufficiency relating to PPS/LEOP can be very successfully treated with modern NIV techniques, achieving long term control, usually from treatment restricted to night time use. The only caveat is that tracheostomy may be required in the presence of severe bulbar involvement with secretion management problems and reduced NIV tolerance. NIV should be readily accessible to all post polio patients with relevant sleep breathing and respiratory muscle problems. Sleep problems not related to a sleep breathing aetiology are more variable in response but good communication between sleep medicine and other specialist inputs is likely to optimise clinical outcome.

The EFNS review\textsuperscript{12} supports a role for respiratory muscle training and, on balance, efforts to maintain respiratory muscle function seem reasonable. Finally, best practice for respiratory care requires facilities for aggressive secretion management where required, i.e. physiotherapy input with a range of cough assist techniques and links to speech and language therapy.
2.5f Key points

► New respiratory symptoms are common in the context of PPS/LEOP but many will relate to non-polio aetiologies.
Initial lung function is important in predicting need for active respiratory support (NIV).
► Serial lung function testing is only helpful in context of the emerging clinical picture.
► Sleep breathing studies are the most sensitive predictor for future NIV. Sleep medicine is an important element in the care of patients with LEOP.
► If breathlessness is the only respiratory symptom and a local VC measurement is normal no further respiratory input is required unless there is a change in clinical picture.
► If the patient has a range of symptoms (most commonly sleep breathing abnormality or sleep disruption) referral to a respiratory unit with sleep medicine facilities is indicated with sleep studies and respiratory muscle tests as previously outlined. Sleep breathing centres are equipped to provide the appropriate type of support.
► If there is very severe respiratory failure with secretion clearance problems the sleep centre should refer the patient to a regional complex assisted ventilation service.

2.6 Pharmacology and pharmacy

There is debate over whether individuals with PPS/LEOP have an increased sensitivity to anaesthetic and muscle relaxant drugs\(^4\). All polio survivors should be viewed as having an increased risk of needing post operative ventilatory support due to unrecognised respiratory muscle involvement in the acute attack and/or undiagnosed PPS.

There is no evidence that polio survivors have an increased propensity to muscle damage from the statin group of drugs. However, it is particularly important that implementing statin therapy in this population is based on an
assessment of reduction of overall cardiovascular rather blood lipid results in isolation. Any evidence of developing muscle damage in polio survivors on a statin should normally lead to withdrawal of the drug while the cause is evaluated.

Polio survivors who develop swallowing difficulty will benefit from pharmacy assistance in establishing the best formulations for their drug therapies.

2.7 Lymphoedema (see annex D for more detail)

In people with PPS/LEOP, lymphoedema can occur for various reasons and often a combination of several:

- The muscle pump action required to move fluid may be compromised if the muscles are weak, the natural walking movement is affected, or the limb is dependent.

- Increased capillary filtration can occur as a result of trauma (e.g. an ulcer due to callipers, or other injury), infection, vein problems, or as an effect of certain medications.

- A primary insufficiency of the lymphatic system may be present but can be difficult to diagnose without investigations. Also the lymphatic system becomes less efficient with ageing and with weight gain.

- Other medical problems such as right heart failure or liver disease can contribute to swelling.

Lymphoedema can be well controlled although it does not usually completely resolve. Early recognition of the signs of lymphoedema allows self management approaches and relevant specialist treatments to be started. This can minimise the risk of further complications such as infection which can be severe and require hospitalisation.
Referral to a lymphoedema specialist is advised so self management advice and support can be given. However, access to services is varied and lymphoedema clinic provision is not standardised in Scotland.

A course of intensive treatment may be required if the swelling is severe and persistent, the limb shape is distorted, or the skin is in a poor condition. Further referral to relevant services such as the vascular specialist may be indicated for some people.

The lymphoedema needs of people with PPS/LEOP should be kept in mind by SMASAC as part of its current scoping work on the condition.

2.8 Orthotic services

Concern about the availability and standard of orthotic services has been a key feature of many of the group’s discussions. The SPPN conducted a review of some of its members’ experiences of orthotic services which provided anecdotal evidence that these were often less than ideal. This has been supplemented by personal testimonies from some of the group’s members and their acquaintances. Similarly, BPF conducted a review of patient experiences of using the NHS orthotics service in part to inform the NHS Orthotics Panel and help gather information that could help to improve the service to BPF members and to orthotics users generally. Specific objectives were to explore:

- What orthoses are used.
- How the process works for users, in terms of waiting times, consistency of the team that treats them, etc.
- How users feel the service should be improve.

A summary of the findings of the review is included at Annex E.
2.8a Orthotic services in Scotland

Strathclyde University is one of only two in the UK providing a Masters degree in Prosthetics and Orthotics, with an intake currently of 30 students per year. The orthotic management of polio survivors is covered in some detail in the undergraduate programme. However, because of the relatively small number of polio survivors with orthoses in regular contact with orthotic services, each individual orthotist may see post polio only occasionally.

2.8b Patient groups

From the orthotic management point of view, there are three main groups of patients whose needs should be considered. Broadly, these are:

- People already in the orthotic system who are going through the process of assessment/fitting of orthosis or regular review.

- People who are known to their local service but may not have been reviewed for some time and may benefit from a review of their needs.

- People who are not known to the orthotic service and do not currently use an orthosis, but who may now benefit from assessment.

In considering these groups, a number of questions arise:

- If individuals are not being seen regularly by the orthotic service, are they being seen by anyone? If so, are other AHPs aware of how and when to refer to orthotics?

- How would we best reach the group who are currently not known to the system, bearing in mind that a number will have some psychological resistance to seeking ‘help’ for a condition that they may regard as something they just have to cope with? Is there sufficient awareness among polio survivors of the potential for late effects to develop?
• What is the level of unmet need, both in patients who could benefit from review and patients who are unknown to the service, and what would be the impact on the service if more people come forward for assessment and review?

2.8c Pathways into the orthotic service

‘New’ patients reach orthotics mainly by referral from orthopaedics, and may or may not have had surgery. GPs cannot currently refer directly to orthotics. Patients known to the system can self-refer, and traditionally would have done, although this is becoming less common. There are not well-developed referral criteria into orthotics for assessment, so there may discrepancies in treatment and management, e.g. surgery or orthotic management. Direct GP referral to orthotics could result in an unmanageable number of new assessments which the service would not be able to cope with. However, if good quality advice and guidance could be developed for GPs to avoid inappropriate referrals, this could be valuable in the future.

The development of best practice guidance for qualified orthotists would be welcome. There are established channels for the dissemination of guidance to orthotists working in Scotland. As a result of the recent Orthotic Review, each NHS Board is required to identify an Orthotic Manager to take forward the recommendations of the review.

Many of the difficulties in orthotic provision are not unique to PPS/LEOP. A recurrent comment in surveys of orthotics users is that it would be more efficient for all concerned if there could be a longer initial consultation which resulted in a well fitted and suitable orthosis rather than a series of shorter visits and serial modifications.
Section 3 – Service model options

3.1 Status quo

Problems with the current configuration and availability of services are mainly related to awareness of the condition and the uncoordinated development of services across the country. Responses to a 2005 petition by the SPPN indicated a range of awareness and knowledge of PPS among organisations and NHS Boards. It was accepted by the Chief Medical Officer (CMO) that although recognition of PPS by the medical profession had improved, recognition and awareness of the syndrome could be patchy, leading to variance in how quickly individuals may be diagnosed and appropriately referred.

3.2 Augmentation of informal network of interested clinicians

The SPPN has compiled a list of ‘interested clinicians’, which is available on their website and supplied to individuals who contact SPPN. The Network continues to encourage awareness and interest in PPS/LEOP among clinicians, but this is likely to progress only slowly and will be focused largely at consultant level in specialty areas such as neurology, respiratory medicine or orthopaedics, where, generally speaking, awareness is less of an issue. As the SPPN has identified, problems in accessing help and advice are more likely at the earlier stages of recognition and treatment: in general practice, physiotherapy and occupational therapy particularly. Since at this level of primary and/or community care, individual professionals are likely to see only a very few polio survivors in their day to day practice, encouraging greater awareness of patient needs by way of an informal network is likely to be more of a challenge. There will also be a role for the Community Health Partnerships (CHPs), both because they are likely to cover a larger number of people with PPS/LEOP but also because of their links to NHS Boards’ local planning partners, which help to integrate people’s health and social care, along with other needs such as housing. This approach will be promoted by essential criterion 4.8 of the NHS QIS neurological standards, which is that the local neurology service has channels of the communication with the
individual responsible for long term conditions in the local CHP or equivalent, to co-ordinate the provision of services, equipment and medication by NHS and social services.

While having identified specialists with an interest in PPS will be of assistance in guiding referral to those individuals, the lack of structure and identified aims and objectives in an informal network is likely to mean that there will be little influence over current service design and development, and change will happen only slowly. Additionally, opportunities for sharing experience and best practice are unlikely to be maximised.

3.3 Establishment of a formal Managed Clinical Network (MCN)

Managed Clinical Networks (MCNs) were first introduced as a concept in the Acute Services Review of June 1998 and this was followed by a Management Executive Letter (MEL) (1999) 10, which defined MCNs as:

"linked groups of health professionals and organisations from primary, secondary and tertiary care, working in a co-ordinated manner, unconstrained by existing professional and health boundaries, to ensure equitable provision of high quality clinically effective services throughout Scotland".

MCNs have since developed for a number of patient groups, from those with small numbers and very specific needs (such as home parenteral nutrition) to more common, long-term conditions (such as stroke or diabetes). MCNs can be organised on a national, regional or local basis, the main determinant generally being patient numbers.

The common aim of MCNs is to facilitate the improvement and consistent, equitable delivery of services to people whose condition means that they require multi-disciplinary care which may involve primary, secondary and tertiary services and a range of clinical and AHP specialties. They also give a strong voice to patients and the voluntary sector organisations that support them. All MCNs should operate according to a recognised evidence base, and usually act as a vehicle for the development of standards, to promote
consistency of services. Managed Care Networks have been developed for conditions where there is a particular need to integrate people’s health and social care needs.

Funding is generally allocated to a MCN to cover its administrative costs (a Network Manager, who may be responsible for more than one MCN), and the cost of backfill for a defined number of clinical sessions to ensure the clinical leadership of the MCN. Each MCN is then expected to detail its objectives and produce a yearly report to demonstrate its progress against these, and after its initial establishment phase, to demonstrate that it contributes to measurable improvement in patient care.

The provision of administrative resource and a defined clinical lead with a recognised allocation of time for network activities would undoubtedly assist in taking forward improvements to the current services for people with PPS/LEOP. The numbers involved suggest that the development of an MCN approach would need to be at regional level, and taking that forward would require further discussions with the Regional Planning Groups. Additionally, the care needs of people with PPS/LEOP may not be seen as sufficiently dissimilar to those of patients with other neurological long term conditions, to merit the establishment of a single condition MCN.

3.4 The role of specialist centres

As already noted, the complexities of PPS/LEOP often require a multidisciplinary approach. At present a patient can be seen in a variety of clinics, often at different locations. This is time consuming and can lead to failure of integration of the various elements.

One potential solution is to establish one or more specialist centres where all the necessary disciplines are present. Such centres have been established in England (London, Liverpool and Newcastle), Ireland (Dublin) and the USA (Warm Springs). The advantages of co-locating services are clear, particularly for those individuals with complex needs. However, many polio
survivors have needs which can be met locally without them having to travel to a specialist centre. There is a risk that establishing a specialist centre would reduce provision of some local services. As yet, there appears to be little cost/benefit analysis on the overall value of specialist centres.

Any proposal to establish one or more such centres in Scotland would need rigorous evaluation, bearing in mind the relatively small number of individuals who might benefit and the widely dispersed nature of the patient population. Comparison would also need to be made against other ways of integrating services better, such as a Managed Clinical Network.

### 3.5 Summary of service model options

Maintaining the status quo appears to be unacceptable. At the very least, the group recommends that consideration should be given to strengthening local services as part of the process of taking forward the NHS QIS Implementation and Improvement Support Plan for its clinical standards for neurological health services. The group also recommends that there should be discussions with the Directors of Regional Planning about the feasibility of developing a Managed Clinical or Care Network approach to PPS/LEOP services.
Section 4 – Role of the voluntary sector

4.1 Scottish Post Polio Network

The fact that a SMASAC working group was convened to make recommendations around the provision of services for people experiencing the late effects of polio is due mainly to the efforts of the Scottish Post Polio Network. Formed in 2001 by a small group of polio survivors who had experienced various problems in accessing advice, support and/or treatment to help with their new healthcare needs, it began to raise awareness of the condition among health professionals and polio survivors themselves, many of whom were unaware that the problems they were experiencing could be related to childhood polio. The Network began to build its membership, to share advice and guidance from other international sources and to campaign for action to raise the profile of PPS/LEOP, and in 2005, took its campaign to the Scottish Parliament. Following on from this, representatives from the SPPN met with the Deputy Chief Medical Officer and the head of the Long Term Conditions Unit late in 2007 to discuss setting up this SMASAC working group, the full membership of which is included at annex H.

During the course of this work, the SPPN and SGHD have worked together on a public awareness campaign, with good results, and on redeveloping the Network’s website. The SPPN continues to act as a source of advice for new and existing members, other polio survivors and their families, and continues in its work to build a network of interested clinicians.

4.2 British Polio Fellowship

Throughout this work, the group has also had contact with the British Polio Fellowship (BPF), a national charity with an obvious interest in services for people with PPS/LEOP. The BPF benefits from a much more established organisational structure, full time staff and a larger membership. It is therefore more readily able to fund research, marketing and development work, and to have a strong voice in policy development. There were clearly many issues in common between the groups; both were concerned with raising awareness
among polio survivors and health professionals, were considering the development of UK-specific guidance in some form, and were looking to improve the processes by which polio survivors are referred, or self-refer, to the services appropriate to their specific needs.

**Other organisations**

The Pain Association Scotland runs staff-led monthly self management groups throughout Scotland, in many cases as part of a service agreement with NHS Boards. Clinicians caring for those with PPS/LEOP should bear in mind the benefits which might accrue from referral to such a group.

Pain as a symptom of PPS/LEOP should benefit from the work currently being undertaken by the Scottish Government’s Lead Clinician for Chronic Pain in developing a service model for pain management in Scotland, linked closely to the work on musculo-skeletal services being taken forward as part of the process of implementing the Framework for Adult Rehabilitation.

Assist UK, also known as AIMS, leads a UK wide network of locally-situated Disabled Living Centres. Each centre includes a permanent exhibition of products and equipment that provide people with opportunities to see and try products and equipment and get information and advice from professional staff about what might suit them best. Assist UK also offer training courses linked to services provided by members. There are five disabled living centres in Scotland (in Dundee, Edinburgh, Elgin, Paisley and Stirling) providing specialist information on aids and equipment as well as other disability related enquiries.

In view of the importance to people living with PPS/LEOP of maintaining their independence, information should be made available to them, either from healthcare professionals or through the SPPN, about the availability of self directed support. That funding allows people to determine their own care package and, if they so wish, to employ people to deliver it.
Section 5 – Recommendations

5.1 Remit
At its first meeting, the group considered and accepted the following remit:
To report to SMASAC on the following issues relating to PPS and LEOP:

- Defining the condition;
- Determining its prevalence in Scotland;
- Raising awareness of the condition, especially in primary care, through adaptation for Scotland of existing guidance; and
- Considering the potential benefits of a Managed Clinical Network approach to the provision of services.

The group’s recommendations in these four key areas are as follows.

5.2 Defining the condition
The definition of PPS, as detailed in the NINDS criteria (Annex A) is widely accepted. For the wider term ‘late effects of polio’ the group recommends that the operational definition as proposed by the Queensland Review is accepted, to describe symptoms arising from:

- Musculoskeletal imbalance.
- Growth retardation.
- Skeletal deformities of affected limbs.
- Respiratory insufficiency.
- Cold intolerance due to circulatory disturbances.

This list is not exclusive and symptoms consequent on the deficit following polio may be added. These would include entrapment neuropathies related to alterations of posture and can occur at any time after the initial poliovirus infection.
The development of new symptoms in an individual considered to have had polio may be due to PPS, LEOP, or the development of an unrelated health problem. It is the remit of primary care to interpret symptoms and refer on to the appropriate professional. New weakness should ideally generate a referral to neurological services whose skills and resources are essential to make a diagnosis of the cause of new weakness.

Presence of any of the following in an individual considered to have had polio should prompt consideration of PPS/LEOP:

- Falls.
- New pain in an area not previously affected.
- New or evolving wasting.
- Sensory symptoms such as tingling or numbness especially in a discrete area (for LEOP only).
- New dysphagia.
- The development of more than one respiratory infection in 12 months requiring antibiotics.
- Any fracture.

As noted in Section 2.10, individuals with PPS/LEOP who develop respiratory symptoms must have appropriate assessment, including exclusion of other causes. Those who have polio related respiratory problems and a significantly reduced vital capacity will require access to sleep studies and may need non invasive ventilatory support.

5.3 Determining the prevalence of PPS/LEOP in Scotland

As described earlier in this report, there would be considerable difficulty in establishing a more accurate estimate of prevalence than that which is currently available based on existing literature. The group therefore recommends, for planning purposes, that the prevalence of PPS/LEOP in Scotland is accepted as between 1,000 and 6,000 individuals.
5.4 Raising awareness of the condition, especially in primary care, through adaptation for Scotland of existing guidance

In its consideration of how best to raise awareness of PPS/LEOP in primary care, the group concluded that focusing on individual GPs was unlikely to yield much benefit in return for the considerable resource that would be required to produce and distribute educational information to each practice.

However, it was agreed that there would be considerable benefit to educating polio survivors about PPS/LEOP and empowering them to have the confidence and knowledge to approach their GP with relevant and reliable information.

During the work of this group, the BPF has produced a booklet on PPS\textsuperscript{17} for exactly this purpose, which gives a clear and informative introduction to PPS and its management. Informal feedback from the Irish Post Polio Network, where a similar guidance booklet has been available for some time, indicates that patient empowerment and promotion of confidence has been its main benefit. There would seem to be little additional benefit to be gained by developing a separate publication for Scottish polio survivors, though SGHD may wish to consider this.

- The group recommends that the BPF publication on PPS\textsuperscript{17} be made widely available to polio survivors and health professionals in NHSScotland. The Queensland Review\textsuperscript{14} should also be made readily available.

- For general practitioners, it was agreed that a simple description of referral pathways would be the most useful tool that could be provided. This already exists in the form of the NHS Direct ‘Map of Medicine’ (MoM) pathway for PPS (see Annex F). However, MoM is not in use in NHSScotland and SGHD should consider whether this particular pathway could be adopted by NHSScotland in a similar way.
It was also recognised by the group that even where individuals and primary care practitioners may be aware of PPS/LEOP, there is little knowledge of how and where to refer, particularly to services such as physiotherapy, community nursing and occupational therapy. Self-referral is, in most cases, possible. However this does not seem to be widely known and the group feels that polio survivors should have a source of information which details self-referral policy and procedure for the range of community-based assessment services in their area.

- Information on self-referral policy and process for community nursing, occupational therapy and physiotherapy services should be collated and made available via the SPPN website. Practitioners receiving self referrals should ensure that the polio survivor’s GP receives relevant information.

For some services, it was agreed that more specific guidance for healthcare professionals may be useful. It was accepted that the extent and quality of the evidence base for this guidance would not be sufficient for a Scottish Intercollegiate Guidelines Network (SIGN) guideline or equivalent, but that Best Practice Guidelines (BPGs) would be helpful. These would be particularly useful to physiotherapy, where there has been varying advice on treatment options, and orthotics, where services have historically been under-resourced and inconsistently delivered. It was also recognised that there may be significant unmet need for orthotic review in the polio survivor population and further attempts should be made to quantify this, since the service was unlikely to be able to meet a sudden increase in demand without adequate planning and additional resource.

- HIS should be asked to consider the development of BPGs for the treatment of PPS/LEOP for physiotherapists and orthotic service providers.
5.5 Considering the potential benefits of a Managed Clinical Network approach to the provision of services

The needs of polio survivors with PPS/LEOP are complex and require input from a variety of clinical and social services. A MCN could be of benefit by formalising and strengthening the work of the “interested clinicians” and by allowing experience and examples of good practice to be shared. Many of the issues faced by polio survivors are similar to those in other long term neurological conditions. The Regional Planning Groups should be asked to consider establishing a MCN for PPS/LEOP alone or in conjunction with other conditions whose patients have similar needs.

SGHD should ensure that the needs of those with PPS/LEOP are kept in mind during the process of implementing the NHS QIS clinical standards for neurological health services, especially through the work of the local neurological services improvement groups which are being set up in each NHS Board. SGHD should also make sure that NHS Boards’ long term conditions executive sponsors are made aware of the recommendations in this report.
Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>BPF</td>
<td>British Polio Fellowship</td>
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<tr>
<td>BPG</td>
<td>Best Practice Guideline</td>
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<tr>
<td>CHP</td>
<td>Community Health Partnership</td>
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<tr>
<td>CMO</td>
<td>Chief Medical Officer</td>
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<tr>
<td>EFNS</td>
<td>European Federation of Neurological Societies</td>
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<tr>
<td>GP</td>
<td>General Practitioner</td>
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<tr>
<td>HIS</td>
<td>Health Improvement Scotland (from 1 April 2011)</td>
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<tr>
<td>LEOP</td>
<td>Late effects of polio</td>
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<tr>
<td>MCN</td>
<td>Managed Clinical Network</td>
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<tr>
<td>MEL</td>
<td>Management Executive Letter</td>
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<tr>
<td>MoM</td>
<td>Map of Medicine</td>
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<tr>
<td>NHSQIS</td>
<td>NHS Quality Improvement Scotland</td>
</tr>
<tr>
<td>NINDS</td>
<td>National Institute for Neurological Disorders and Stroke (USA)</td>
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<tr>
<td>NIV</td>
<td>Non invasive ventilation</td>
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<tr>
<td>OT</td>
<td>Occupational therapy</td>
</tr>
<tr>
<td>PaCO2</td>
<td>Arterial carbon dioxide partial pressure</td>
</tr>
<tr>
<td>PPS</td>
<td>Post polio syndrome</td>
</tr>
<tr>
<td>SaO2</td>
<td>Arterial oxygen saturation</td>
</tr>
<tr>
<td>SGHD</td>
<td>Scottish Government Health Directorates</td>
</tr>
<tr>
<td>SIGN</td>
<td>Scottish Intercollegiate Guidelines Network</td>
</tr>
<tr>
<td>SMASAC</td>
<td>Scottish Medical and Scientific Advisory Committee</td>
</tr>
<tr>
<td>SPPN</td>
<td>Scottish Post Polio Network</td>
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<tr>
<td>VC</td>
<td>Vital capacity</td>
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</table>
Annex A – NINDS diagnostic criteria for Post Polio Syndrome

NINDS set out the following as diagnostic criteria:

- Prior paralytic poliomyelitis with evidence of motor neuron loss, as confirmed by history of the acute paralytic illness, signs of residual weakness and atrophy of muscles on neuromuscular examination, and signs of nerve damage on electromyography (EMG). Rarely, persons have subclinical paralytic polio, described as a loss of motor neurons during acute polio but with no obvious deficit. That prior polio now needs to be confirmed with an EMG. Also, a reported history of nonparalytic polio may be inaccurate. A period of partial or complete functional recovery after acute paralytic poliomyelitis, followed by an interval (usually 15 years or more) of stable neuromuscular function.

- Gradual onset of progressive and persistent new muscle weakness or abnormal muscle fatigability (decreased endurance), with or without generalised fatigue, muscle atrophy, or muscle and joint pain. Onset may at times follow trauma, surgery, or a period of inactivity, and can appear to be sudden. Less commonly, symptoms attributed to PPS include new problems with breathing or swallowing.

- Symptoms that persist for at least a year.

- Exclusion of other neuromuscular, medical and orthopaedic problems as a cause of symptoms.
Annex B – Prevalence estimates

There are several studies which have aimed to quantify the prevalence of PPS in polio survivors, using a variety of different study methods. Results are summarised below:

<table>
<thead>
<tr>
<th>Author (country and year of study)</th>
<th>Proportion of polio survivors found to have developed PPS</th>
<th>Study notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gilhus (Norway 1998)</td>
<td>15%</td>
<td></td>
</tr>
<tr>
<td>Takemura et al (Japan 2004)</td>
<td>85%</td>
<td>Questionnaire survey</td>
</tr>
<tr>
<td>Halstead et al (USA, 1983)</td>
<td>42-87%</td>
<td>Questionnaire survey</td>
</tr>
<tr>
<td>Ahlstrom (Sweden, 1993)</td>
<td>20-80%</td>
<td>Medical records review</td>
</tr>
<tr>
<td>Halstead &amp; Rossi (USA, 1987)</td>
<td>75%</td>
<td>Clinical study</td>
</tr>
<tr>
<td>Codd et al (USA, 1985)</td>
<td>22.4% of paralytic cases</td>
<td>Questionnaire survey</td>
</tr>
<tr>
<td>Windebank et al (USA, 1995)</td>
<td>60%</td>
<td>Clinical study</td>
</tr>
<tr>
<td>Ramlow et al (USA, 1992)</td>
<td>28.5% of paralytic cases</td>
<td>Questionnaire survey</td>
</tr>
</tbody>
</table>

Variation in the findings may be due in part to the differences in study methods and the selection of the studied groups. Risk factors identified as associated with the development of PPS include: greater severity of illness at acute phase, greater recovery after acute phase, older age at time of acute phase, permanent impairment after recovery, female gender, longer time interval since acute phase, and possibly, increased physical exercise (Trojan & Cashman, 2005).

Some of these, and other studies, have estimated the population prevalence of PPS, or of polio survivors in the population. These include:

- Gilhus, 1998 (250 per 100,000 population polio survivors)
- Takemura et al, 2004 (18 per 100,000 population PPS)
- Ahlstrom et al, Sweden (186/100,000 population PPS)
- Halstead (1995) (269 per 100,000 polio survivors)
- Lonnberg, 1993 (157 per 100,000 population PPS)
Pentland et al. (1999) used the studies above to assume a prevalence of 200 per 100,000 population polio survivors and a population of .75 million in Lothian. This would give an estimate of around 1,500 polio survivors in Lothian and, if extrapolated to the whole of Scotland population of 5.1 million, 10,200 polio survivors in Scotland.

If Pentland’s conservative figure of 20% of these individuals go on to develop PPS, that would indicate 2040 individuals in Scotland. However, this is based on extrapolation from previous studies and it is not clear how applicable the findings of these may be to the Scottish population.

What we do know about polio incidence in Scotland is derived from notified cases. There were 6792 notifications of polio in the period 1934 to today. We also know how many people died in this period with a cause of death recorded as acute poliomyelitis, and if we assume that deaths in this period occurred in individuals notified in the same period, this brings the notified cases down to 6203.

These data have some limitations; we do not know how old these individuals were at the age of onset, but given that the notifications go back to 1934 we can be sure that this includes everyone up to at least 73 years of age today, whose polio was notified to the health authorities. We do not know the extent of under-reporting, which raises some questions about how many more polio cases might have occurred in this period that are not captured in these data. We could possibly assume that some milder cases may have been treated at home, but quantifying this may be difficult. This figure of 6203 also does not take into account deaths from other causes during the intervening years, or migration into or out of Scotland.

If we were to assume that the notifications above represent all the paralytic cases (which are the most likely to go on to develop PPS) and that all of the individuals identified as having survived the acute phase are still alive, that would give us a prevalence of 121 per 100,000 population polio survivors in Scotland. Using a
figure of 20% of these individuals going on to develop PPS, we could expect there to be 1,240 individuals affected by PPS in Scotland today, or 24 per 100,000 population.

Since PPS most commonly develops 2-4 decades after acute phase and the last major epidemic occurred in 1958 we can safely assume that the current cohort, once identified, will not increase significantly.

Based on other studies and what records we have, the likely number of polio survivors in Scotland today is probably between 6,000 and 10,200. The table below illustrates the total numbers with PPS for a range of proportions of the cohort who may have PPS, from 20% to 60%.

**Possible prevalence of PPS in Scotland based on different numbers of polio survivors and proportions developing the syndrome**

<table>
<thead>
<tr>
<th>Proportion of people developing PPS</th>
<th>Number of polio survivors</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>6000</td>
</tr>
<tr>
<td>20%</td>
<td>1200</td>
</tr>
<tr>
<td>30%</td>
<td>1800</td>
</tr>
<tr>
<td>40%</td>
<td>2400</td>
</tr>
<tr>
<td>50%</td>
<td>3000</td>
</tr>
<tr>
<td>60%</td>
<td>3600</td>
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Annex C – Report from Scottish Public Health Network

Potential for surveillance

In seeking to consider the potential for surveillance for post-polio syndrome and achieve a more accurate picture of prevalence, the first issue to be addressed is that of case definition. This is not as straight-forward as it may seem. For example, whilst PPS is usually described as a condition that affects polio survivors some years after recovery from the initial acute phase of poliomyelitis, actual diagnosis is based on a medical assessment of a patient against set criteria (such as the criteria set out by NINDS).

Even applying such criterion based approaches can be prone to a high degree of variability as a consequence of either the spectrum of residual weakness experienced by people with PPS or by the number and complexity of presenting co-morbidities.

The variability in reported estimates of PPS prevalence derived from research studies described above are clear evidence of these difficulties in case definition.

Describing PPS in data recording systems

One of the immediate consequences of this requirement for a PPS diagnosis on the basis of a medical assessment against criteria is that the condition is very hard to identify in existing, routine data systems of the type used in Scotland. Whilst coding conventions for PPS do exist within – for example – the WHO International Classification of Diseases (10th Revision 2007) includes codes for the sequelae of poliomyelitis – their use and recording within data sets is variable. Where a definite diagnosis has been made, it may be recorded centrally on either GP systems or in hospital out-patient records. However, alternative codes which reflect more fully the presenting illness or concern may also be used.
Linking clinical datasets

One clear possibility for some form of records linkage would be to use all existing healthcare records to identify those individuals with any diagnosis of “polio”, and then use General Registrar’s Office for Scotland death registrations data to confirm those still alive. From there, specific reviews could be undertaken via their existing medical practitioners. Whilst this approach has its attractions, the potential complexities of seeking approval to use such data sets for this type of purpose cannot be underestimated. The ethics of such an approach would also require careful consideration.

The potential for using only medical records linkage approaches to the identification of people with PPS has been explored with the Information and Statistics Division of NHS National Services Scotland (ISD). Two general approaches have been considered.

The first is based on a forward linkage, using an initial identification of an individual as having suffered from acute, paralytic poliomyelitis. Using the NINDS definition a basis for a matching algorithm, it may be possible to identify those for whom after at least 15 years, health care records show symptomatic presentations / investigated conditions which may be associated with PPS. These would have to exist without any alternative, substantive diagnosis based on similar presenting symptoms. These would need to explore both Scottish Morbidity Records (SMR) and GPASS records.

The second approach explored was a backward linkage, based on an algorithm which explored SMR and GPASS records for symptomatic presentations which were used to then track back through records for confirmation of previous acute, paralytic poliomyelitis and no evidence of other possible diagnoses.

The view from ISD was that while such linkage algorithms could be technically possible, they were unlikely to be effective ways of identifying cases. Leaving aside the potential for error associated with the variable quality of older data set, the complications of changes in coding conventions or of the simple availability of
data in computerised formats, the absence of sufficiently well defined criteria for describing the constellation of symptoms of interest would be highly problematic. Defining the symptoms too loosely would provide for a very large number of false matches that would have to be excluded. Setting too narrow a set of parameters would exclude potential cases of interest.

It was also noted that confirmation of a diagnosis of PPS would always have to be undertaken on the basis of a medical opinion, even if the focus was being identified from computerised data.

**Establishing disease registration**

One potential way forward would be to establish a PPS disease register. Whilst a full consideration of the specific configuration of such a register would require much greater detail that can be afforded in this paper, the potential for such a register is clear.

In this regard the approach taken by the British Paediatric Surveillance Unit (BPSU) is notable in that it uses a passive reporting mechanism from clinicians to provide specific cases that can then be followed up in a more structured way by those undertaking the specific surveillance.

Whilst such an approach is clearly within the domain of research, such an approach could allow for the development of a more permissive register in which people with PPS give clear consent for their data to be stored and used more formally for surveillance purposes.
Annex D – Lymphoedema

Recognising the signs of lymphoedema

• Swelling that may initially reduce if the limb is raised.
• Feelings of tightness, heat or tingling in the limb and or trunk area.
• Difficulties with tight clothing or footwear.
• Changes in the skin ranging from dry, itchy skin, to scaly weeping skin, redness and infection, or blister-like changes called lymphangiectasia (bulging lymphatics). Eventually the skin becomes thickened or uneven due to papillomatosis (a cobblestone appearance).

Stemmer’s sign (the inability to pinch the skin at the base of the second toe) is a diagnostic sign of lymphoedema. Other investigations such as lymphoscintigraphy may be undertaken but can be costly and inconclusive.

Self management of lymphoedema

Support is required with various aspects of self management including:

• Skin care: the skin should be kept clean and well moisturised. Clothing and shoes should be well-fitting and supportive, and socks changed daily where possible. Care is taken to reduce the risk of skin injury, for example from a scratch or insect bite, as this can lead to infection. A two-week course of antibiotics may be required if cellulitis (tissue infection) develops.

• Exercise and movement: this may include walking, swimming, specialist exercise and movement classes or physiotherapy advice, as relevant to the individual.

• Wearing compression garments such as stockings or sleeves: these are usually worn daily and are fitted by a trained practitioner such as the lymphoedema practitioner. There are specific lymphoedema garments that help to reduce swelling available on GP prescription, on the advice of a lymphoedema specialist.
• Other support with understanding lymphoedema, weight management, lifestyle changes, emotional wellbeing, and self-massage may be also given.

**Specialist treatment of lymphoedema**

This can include intensive courses of daily treatments aiming to reduce the swelling, improve the skin condition and reshape the limb to allow fitting of compression garments. Each treatment may combine manual lymph drainage massage with application of a layered bandage to the swollen area. Specialist exercises are given and other approaches such as kinesiotaping (a thin adhesive tape on the skin) may be used.

Diuretics are not advised for lymphoedema, as they can lead to dehydration and do not improve the lymphatic system function.
Annex E – BPF orthotic services survey – key findings

The research was conducted via a self-completion survey, which was sent to 2,000 BPF members in April 2008, and generated 862 responses (43%). While it should be noted that these responses were received from members from all over the UK, the SPPN’s own research seems to indicate that Scottish polio survivors have similar concerns as illustrated by these results.

465/862 respondents identified themselves as using orthoses, defined as “specialist footwear, callipers, crutches, walking frames and similar”. The majority of respondents had used orthotics for 30 or more years. As the BPF survey commentary notes, this indicates the need for the specialists ‘ . . .to keep their patients up to date with new developments; since materials must have developed a great deal since these people first had polio or needed orthotics.’

Key findings of the BPF orthotic survey

- 17% of respondents never see the same team and 12% do so only occasionally.
- Respondents are broadly satisfied with the competence and care they receive. Overall, the proportion that is not satisfied is as follows:
  - 21% with the competence of the Technician
  - 19% with the competence of the Orthotist
  - 15% with the care they receive from the team
- 19% of respondents said that they wait 7 weeks or more for an assessment. Only 2% feel this length of wait is reasonable.
- Once they arrive at the assessment, there are mixed views about it. 31% are given as long as they feel they need in the appointment, whereas 26% are given only 10 or 15 minutes.
- 7% of respondents have never seen an Orthotist and 30% have never seen a Technician.
• Despite the length of time they have used orthotics, 29% of respondents have never been re-assessed, to ensure the suitability of their aids and 44% have never had discussions with their specialist about other products or treatments.

How does the service need to be improved?
On this question, it was noted that some respondents are very satisfied with the service they receive. However, around one fifth (and sometimes more) are not satisfied. There were many individual comments made about the one thing that would improve the service. The top three mentions were:

• Longer appointments are needed
• More modern materials / styles should be provided
• They need direct contact with manufacturers

Many respondents also included additional comments, the key themes being:

• The service is getting worse and Orthotists often are located in “back rooms” with poor facilities for medical staff and patients
• Patients often give up after they have tried, in vain, to obtain orthoses that “work” for them and are comfortable
• On-site manufacture / repair is infinitely better than sending orthoses off-site (often many miles away) and frequently having to send them again for more adjustments
• The medical service should listen more to patients, who have many years' experience and a really good idea of what will work for them

On several measures, very variable experiences were reported, for instance, just over one third of respondents reported that they could be reassessed whenever they request it. However, 29% had never been re-assessed. Bearing in mind how long these people have used orthotics, clearly that means that potentially, some people are living with very out of date aids.
Telecare and Other Technologies to Support People with Disabilities and Long Term Conditions

“Telecare – the Vision

Telecare is a term that covers a range of devices and services that harness developing technology to enable people to live with greater independence and safety in their own homes. The opportunities arising from Telecare have been rapidly expanding as the underlying technology has become more sophisticated and its uses have been explored with imagination and creativity.”
(Seizing the Opportunity: Telecare Strategy 2008-2010)

What are the symptoms of Post Polio Syndrome?

“Symptoms include the onset of new weakness or abnormal fatigue in previously affected or unaffected muscles, a general reduction in stamina, muscle and/or joint pain, muscle atrophy, breathing, sleeping and/or swallowing problems or cold intolerance. Symptoms may lead to loss of endurance or function.”

http://www.britishpolio.org.uk/default.aspx

How can these technologies help people?

Telecare technologies can assist people in many ways:

• By increasing independence and choice for individuals.
• By maintaining and promoting independence, safety and security to improve an individual’s quality of life.
• By enabling the individual to live at home longer and prevent them having to move from their home to higher levels of care.
• By giving carers effective support, respite and peace of mind.
• By preventing inappropriate hospital admissions.
• By facilitating an individuals’ early discharge from hospital.
• By helping to manage risk in the home and reduce accidents and falls.
• By enabling agencies to provide improved and focused care delivery.
Types of Telecare Technology to support People with Post Polio Syndrome

DESCRIPTION AND EXAMPLES

Telecare
Usually managed by Social Work and is a 24/7 service. Can be a basic Alarm unit which links into a contact centre, staff there can initiate the most appropriate response i.e. Community Alarm Service. Alerts can also be set up to be responded to by someone else in the house.

The range of alarms, detectors and sensors include:
smoke, gas, CO2, flood, fall, temperature extremes, occupancy sensors, epilepsy monitors, internal pagers, cooker shut offs, etc.

Case study example
Mrs Brown is 75 and lives with her daughter who works full time. Mrs. Brown has mobility and balance problems and is at risk of falling.

She has also become a bit forgetful, and has flooded the bathroom twice, and burned a number of pots in the kitchen. If she drops something, she cannot pick it up, which can cause hazards.

There are concerns about her safety and ability to continue living with her daughter.

Mrs Brown is up often overnight for the toilet, and her daughter is afraid she will fall. She finds it difficult to reach for light switches as she uses a walking aid.

Mrs Brown was helped as follows:-
• She was supplied with a community alarm unit and tilt/fall pendant
• She was referred to a ‘falls management programme’.
• Supplied with detectors for flood, smoke, and gas.
• Passive infra-red (PIR) movement sensors were placed at her bed and leading through to the toilet, as she gets up for the toilet overnight, lamps/lights go on in sequence as she moves through the house to the toilet.
• A pillow buzzer that is programmed to vibrate when the PIR sensor is activated, lets her daughter know that Mrs Brown is up. She can then listen for her mother’s safe return to bed.
• The contact centre responds to alerts during day.
Assistive Technology – Environmental Controls

Usually managed by the Health Services. These systems work with a main controller, which controls home devices that are operated by infra-red or radio frequencies (a very sophisticated remote controller).

The controller scans through programmed options with visual and/or audio feedback. There are a range of switches which give people with physical disabilities the ability to have some choice and control over what they do in their own homes. Because of the patchy nature of polio, a survivor may have enough hand function to press a switch, but be unable to reach it, an environmental control is one solution that might help that. For those with very poor or no hand power, switches needing very minimal movement are available.

The range of functions it can operate includes:
Door intercom, door entry, door openers, hands free telephone, home entertainment, curtain openers, fans, radio, electrical heaters, computers etc.

Case study example
Michael is 54 and lives with his wife who works full time. He is a wheelchair user with limited use of his right hand and he fatigues easily. He has great difficulty reaching and operating switches and controls for most household appliances and is unable to open and close doors. When alone Michael is confined to the house.

Michael was provided with an environmental control system, and now has control over:
- A full door entry system including intercom; door release; and door opener.
- Lights and lamps in his bedroom and living room.
- All of his home entertainment in his living room and bedroom.
- His profiling bed.
- Access to his community alarm.
- Switching on his computer.
- Temperature control.

Telehealth monitoring

Remote monitoring of people with long term conditions such as respiratory disease, cardiac disease, diabetes etc. to promote proactive management, prevent hospital admissions, speed up discharges and aid self management.

These systems operate via a unit in the individual’s home which has attachments linked to the unit which can measure and monitor ECG, blood pressure, heart rate, weight, circulating oxygen, respiratory function, bloods for diabetes and clotting. Individual’s normal parameters of measurements are logged. The measurements are sent to one point where they are received by a clinician.
The system triages the results with a ‘red, amber, green’ alert so that the clinician can target only those people whose measurements give rise for concern.

**Case study example**

Mr A is 64 and lives with his wife. He has respiratory problems which severely limits his activities and his life. He is considered to be uncooperative with his treatment and medication. He has had 2 hospital admissions in the last 3 months of several days duration and he does not like being in hospital.

Mr A was provided with a telehealth monitoring system. His normal parameters of blood pressure, heart rate and circulating oxygen were gathered. He checks these measurements daily, and submits the results via broadband to a secure website. Mr A is taking a more active and proactive role in his condition, and instigating calls to the clinicians when he identifies that his measurements are changing. As changes in his condition are identified quickly, medication or other treatments can be adjusted as necessary. Mr A avoids unnecessary hospital admissions and is much happier at being treated at home.

**Smart housing**

A combination of Telecare and smart house technologies involving almost all aspects of the home environment to help people live safely and independently. By combining technologies for sensing, analysis, control and communications it can support people with a wide range of physical and cognitive needs.

It takes into account the context of events, either in terms of what is happening at that time or has happened in the past, and then reacts in the most appropriate way for that situation.

This could be to call for assistance, prompt the user on the most appropriate course of action, or take no action itself.

**Case study example**

David is an 18 year old male with mild learning disability and some physical disabilities. He lives with his parents and brother but wants to live independently. His parents are concerned about his ability to manage independently and for his safety.

He is assessed by having a weeks stay at the SMART house to determine his needs and any technology which might help. At the end of the week there is information to show how David has managed on his own. It details which alerts have been activated and how often. There is also information to show whether David responded to these alerts appropriately. From this information appropriate technologies to support David can be supplied.
Wheelchair use in LEOP

Two problems cause particular concern in post-polio: the need to begin using a wheelchair after many years of independent mobility; and transition from manual self-propulsion to a powered wheelchair.

In the first of these, the concern arises in the determination of people who have had polio to retain independence. Transition to using a wheelchair may therefore be seen as a defeat, or even giving in. However, wheelchair mobility in many cases needs less energy than walking, especially walking with a grossly impaired gait. Wheelchair use can also spare the strain on joints in the legs (although there can be demands on upper-limb joints). Thus with advancing muscle weakness, joint degeneration, or declining exercise tolerance, transition to wheelchair use can be a positive move, allowing more social activity (provided the environment does not provide obstacles). A further issue is people who fall frequently: a wheelchair can be much safer. However, health professionals advising such a change need to be sensitive to the anxieties that someone with polio may experience at this point.

As post-polio progresses, however, self-propulsion can give rise to its own problems. Weakness and poorer exercise tolerance may make self-propulsion hard, especially when the weakness is in arm or trunk muscles. In these circumstances, some authorities believe muscle weakness could be accelerated by self-propulsion. Joints in the arm (especially the shoulder) can become painful, and arthritis can deteriorate. Powered chairs may then become necessary. Wheelchair users then need to consider statutory or private sources of chairs.

NHS provision of wheelchairs has to date been limited to those unable to walk or self-propel indoors. Post-polio survivors have sometimes reported feeling disadvantaged by this, as they may be able to walk short distances, but fatigue rapidly; and some are concerned that continued self-propulsion can be harmful. In fact, NHS powerchair prescription is possible if it is medically inadvisable to self-propel; and the conditions for NHS provision are currently under review. In addition equipment to preserve employment, including powerchairs where appropriate, can sometimes be funded by the Department of Work and pensions “Access to Work” scheme.

Powerchairs can sometimes have additional features, such as seat tilting, or elevation of the seat to allow access to high tables or shelves. These features may allow longer tolerance of the sitting position, or increase independence. If the user cannot manage standard joystick hand control, a variety of special controls can be fitted, though these are rarely successful in outdoor environments. Taken together, these additional features can assist the post-polio survivor to continue independent mobility in most cases.
Annex H – Membership of working group

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