

Caring & Planning for the Future of Post Polio Syndrome Survey Results

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Victoria Inc.*

October 2021

Introduction

Due to our extensive advocacy work, we made the decision to gather real current data of the experience and future needs of those who are suffering from Post Polio Syndrome. The survey was sent out to all members and had a 53% response rate.

Thank you all for sharing your experiences with us. We acknowledge there were many harrowing and heartbreaking stories and experiences shared in the survey. We believe it's important that their experiences are recognised, however have chosen not to include those that may cause grief and harm to the individuals and those reading this report.

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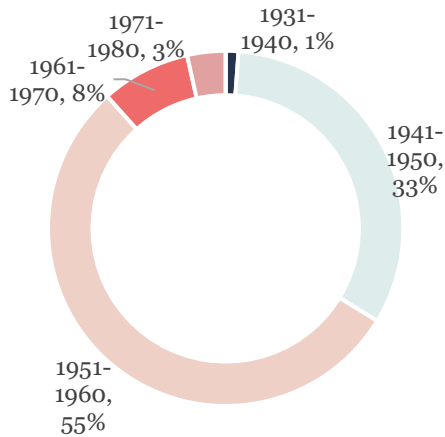
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Diagnosis, when & where (Q1-3)

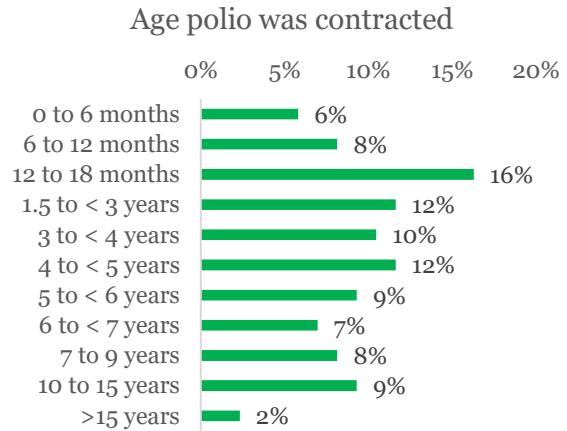


Polio was largely contracted in Australia for most respondents (74.4%), with other locations including Europe, Africa, North America, and Asia.

Most respondents reported contracting polio from 1941 to 1960 (87.2%). For the full break-down, see the table below.



The age of contraction of polio ranged from 6 weeks to 22 years old.



Post-Diagnosis Experiences (Q4)

47.7% of respondents said that they did experience quarantine (3.5% were unsure). From those that did experience quarantine, 48.8% reported spending time at Fairfield Infectious Diseases Hospital, 12.2% at the Royal Children's Hospital Melbourne, with the remaining not specifying where or having their quarantine spread over home and/or other hospitals/locations.

Did you have paralytic polio? (Q6)

- **80.2%** of respondents reported having paralytic polio.
- When providing more details, the use of calipers was widely recalled, followed by splints and braces.

What was quarantine like?* (Q5)

Note: With 98% of respondents being under 15 years old at the time, these themes reflect experiences during childhood. The common themes in these stories emphasise the reality of these experiences. The impact of isolation continues to be seen throughout their lifespan.



Isolation & Loneliness

This occurred in half of the stories about people's experience during this period. Some comments included:



“Extremely lonely. Once a week visit allowed. My only friend was my ... doll”
“Separation from my family was traumatic as they lived in the country”
“Was isolated and removed from my family at [hospital] for months without visitors. I was very scared I remember but confused about where my parents were no explanation was ever given”

Depressing, difficult, traumatic

Many stories of your experiences could be described using the above words:



“Traumatic ... Felt forgotten”
“Horrible, I remember hearing the Iron Lung Machines, I was placed in an iron bar cot (like a cage) could not lift my head!”
“The treatment was super comical no care or concern totally lacking in dignity and lacking in consideration from my perspective.”
“[My mother] not happy [about having to care for me] and years later I was told she [would have] preferred to put me in an institute.”

Anxious, worried, confused, scared

In other stories, feelings of anxiety and worry were experienced. People also said they felt scared, confused, and didn't know what was happening:

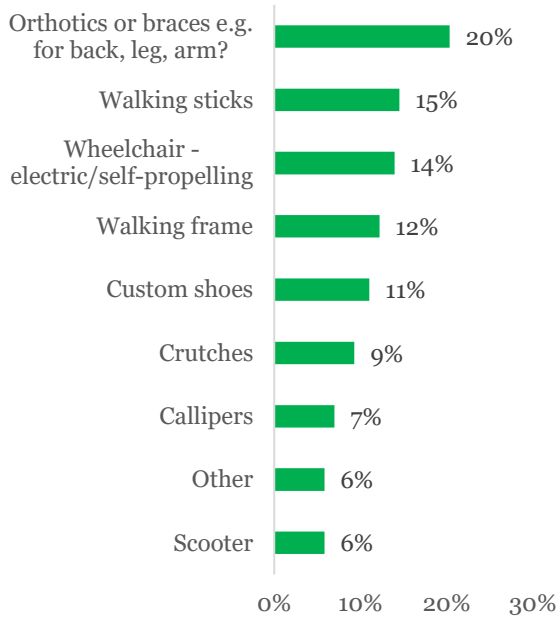


“My parents told me later, they were very anxious and thought I could die.”
“I was very scared I remember but confused about where my parents were no explanation was ever given.”
“Frightening, lonely Told if I misbehaved, I would be put in the mental asylum”
“I can imagine it was pretty horrific for my mum and dad, as they were made to feel that it was their fault for not having me seen to sooner, but they were just following what the family doctor advised them to do.”

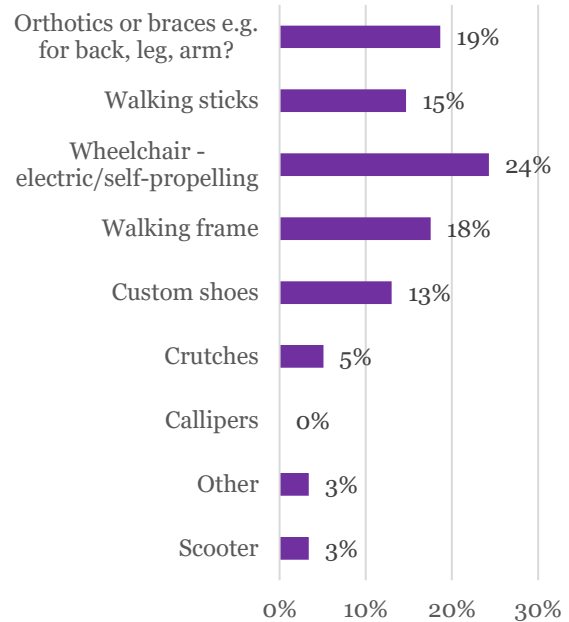
*This question had the option of selecting multiple responses, or comments contains multiple themes

Aids & Assistance (Q7-8)

The assistive aids/technology being **currently** owned or used include*:

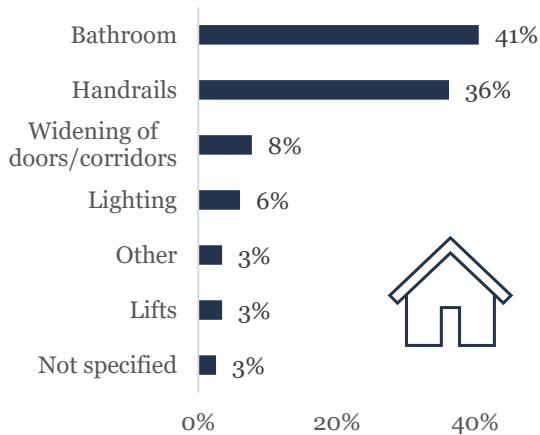


The following are what people are expecting to need in the **future***:

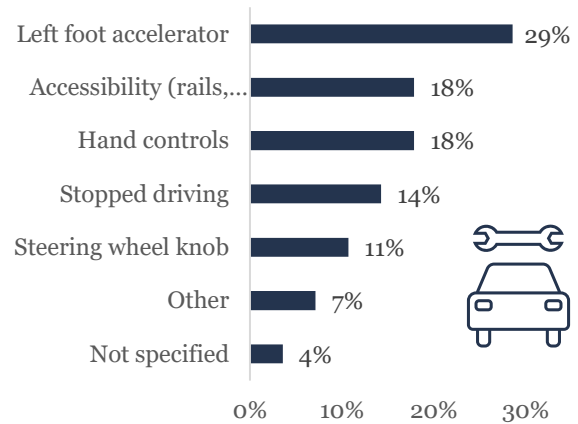


Home & Vehicle Modifications (Q9-10)

Current **home** modifications*:



Current **vehicle** modifications:



Will you need **home** or **car** modifications in the future? (Q11)

28% said yes

28% said no or probably not

24% said maybe

19% were not sure

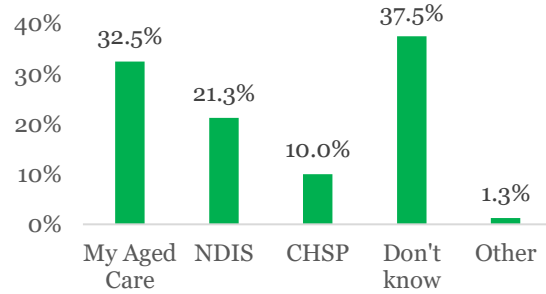
*This question had the option of selecting multiple responses, or comments contains multiple themes

Use of services (Q12-13)

Are you a recipient of My Aged Care of NDIS or any other services*?

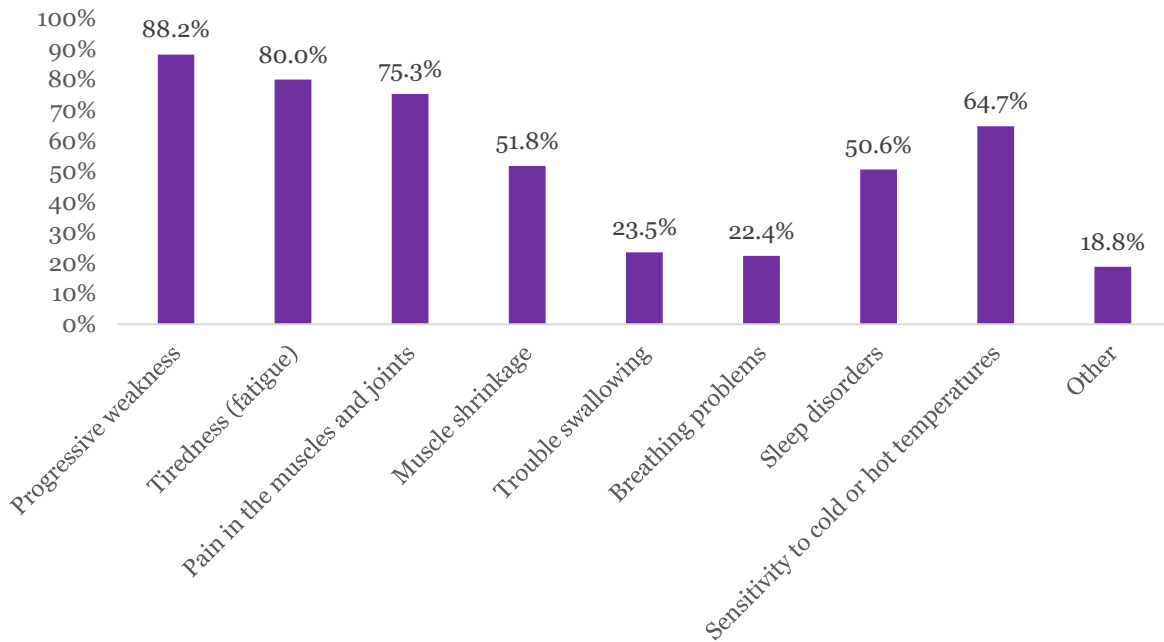
- 38.8% said they were with My Aged Care
- 15.3% were with NDIS
- 12.9% were with Commonwealth Home Support Program (CHSP)
- **24.7% were not a recipient of any services.**
- **4.7% did not know** what services they were being provided

Support scheme preferences*:

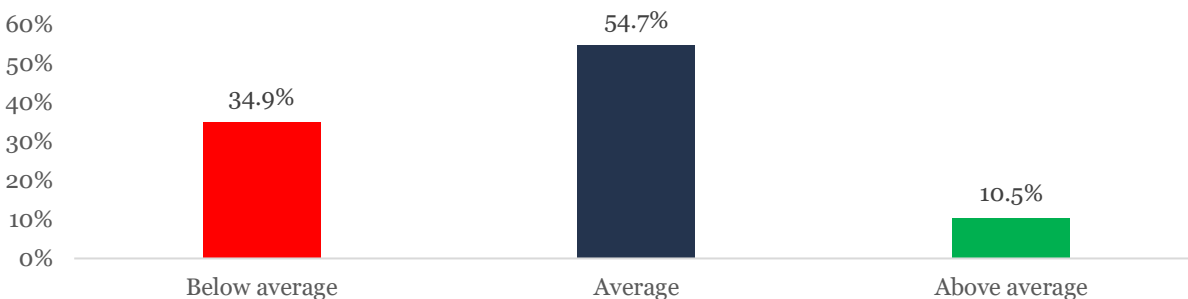


- "They're all inadequate"
- Support for My Aged Care included trust, excellent service, working well.

Post-Polio Symptom Experience* (Q14)

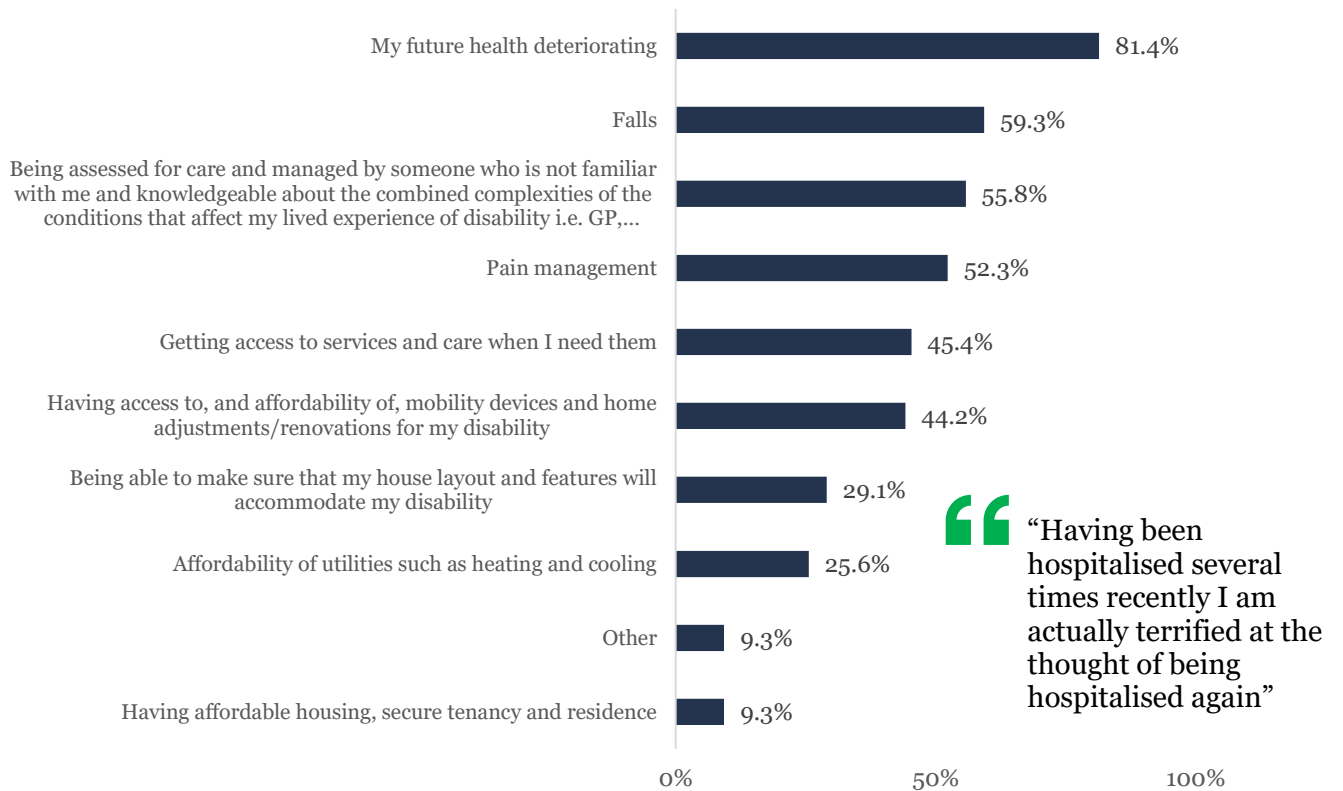


How would you rate your current health status? (Q24)



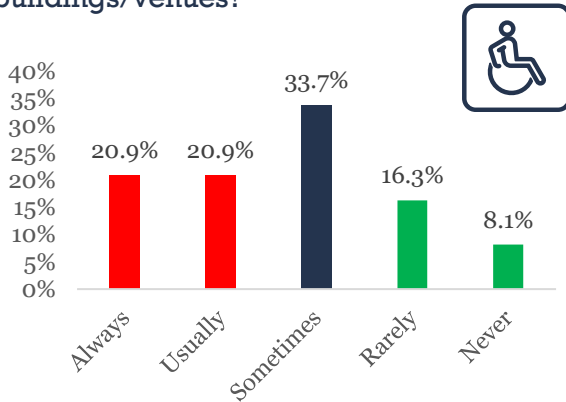
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Greatest fears in relation to post-polio syndrome & impact on accessibility health needs* (Q15-18)

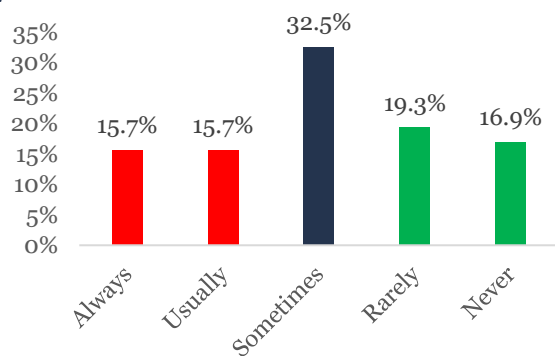


Note: Concern regarding affordability of heating and cooling is particularly important for this population, as symptoms of post-polio syndrome can include both cold and heat intolerance.

How often does your disability affect your ability to negotiate and access public buildings/venues?



How often does your disability affect your ability to negotiate and access public transport / taxi / Uber / Maxi Taxi / driving your own car?

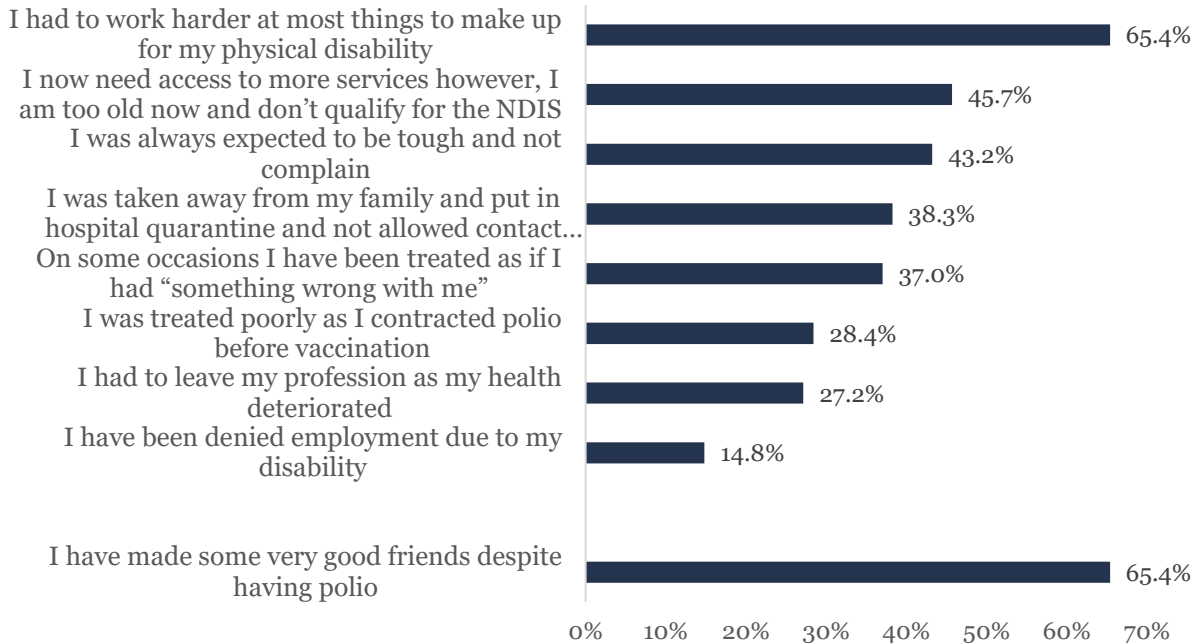


How do you manage if your disability affects your ability to access the above?


- **25%** persevere “Try harder, plan better, rest before and after outings, OR just don’t go.”
 - **17%** friends & family “Stay home, don’t venture out. No visitors, alone 99% of the time”
 - **15%** stay home “Ask those around for help, or at worst find a taxi, put in formal complaints, get frustrated.”
 - **13%** use a taxi service “Work through the pain”
 - **8%** ask for help “If I can’t cope I don’t go”
- “I sit still and wait until the pain or fatigue passes”

*This question had the option of selecting multiple responses, or comments contains multiple themes

Impact of Polio on your life* (Q20)



Impact on Family & Friends* (Q19)

- **34%** no impact “Its difficult to participate with grandkids outdoors but now some are now old enough to not require chasing. So they don't see me as the playful type.”
- **21%** said family & friends were supportive “Unable to visit my married children & grandchildren due to inability accessing their well-established homes which require modifications/alterations”
- **9%** indicated being unable to attend events or participate with friends & family “Annoys them as I cannot do what they do” 
- **6%** said their family and friends were worried “My family have never acknowledged my limitations or physical impact of polio, never shown any empathy at times I struggled, expected me to stop my life to help them but always too busy if shoe on other foot”
“More socially isolated because of pain, lack of sleep, lack of energy, and lack of mobility to attend some outings.”

Further Support (Q21-22)

Satisfaction with current medical and allied health professionals' support and understanding of your health needs:

- **39%** range from very dissatisfied to neither satisfied nor dissatisfied
- **61%** satisfied or very satisfied

Further needs to manage post-polio syndrome that you are not able to access*:

- **50%** services under the NDIS
- **47%** mobility support
- **32%** home renovations



“They are ill-trained to assess my needs when I have had so many years running my own life as a disabled person.”

“Prefer NDIS but not eligible” (from Q12)

*This question had the option of selecting multiple responses, or comments contains multiple themes

Improving physical, emotional, social, mental, cultural, or spiritual health (Q23)

42% responded to this question. The areas where support was needed included knowledge of help, psychological support, and improved (health) services.

“Knowing I could get help when it becomes necessary”

“If I was sure medical practitioners actually knew about my problems and cared and if St Vincent's expanded its limited services”

“The Doctor [looks] at his computer then **[dismisses] me** ... he and **others [are] not interested!** Changed doctors but all [are] the same!”

“Much needs to be done to improve mental health assistance”

“By more people understanding and support from our government”

“I do now feel **very depressed** due to not coping with housework & useless workers who can't even make a bed. **Frustrating** when you can't get into your bed.”

“Just knowing there is help available if needed”

“Removal of irrational stigma imposed by officialdom.”

“Employment discrimination all my life, and now banned from the NDIS. **I feel unfairly punished.**”

“Psych support for anxiety & depression”

Final Comments (Q25)

“Living with a disability is really not so easy... **not knowing** much of what is going on with your body. And it is more difficult to explain your pain to others.”

“... I am resigned to the fact **that I will have to just take one day at a time.** And take Pain Medications when needed. I am unsure of what else would be a help for me?”

“Strengths are often found through adversity”

“I have become **more depressed** with age.”

“... I don't know enough about my condition”

“Like many survivors I **knew nothing** about PPS until the last six months... A lot of sharing is needed.”

“**Public awareness** of our needs and condition. I speak at community groups but that is limited. Perhaps press / media releases would be helpful.”

“Getting professional services such as surgical shoes and calipers repairs is hard”

“It is **very frustrating** that the support is not available with aged care workers who are milking our system”

“There appears to be **insufficient research** into Post Polio Syndrome, resulting in substandard assistance and medical care... there is an expectation that the ageing cohort of people suffering from PPS will soon disappear given that Polio has largely been eradicated some time ago”

“Sadly, we seem to be the forgotten people.”