

Position Paper

Number of Polio Survivors living in Australia who may be experiencing the Late Effects of Polio

Polio Australia considers that there are **tens of thousands** of polio survivors living in Australia who may be experiencing The Late Effects of Polio. This estimate emphasises the significance of the polio survivor numbers, without using a specific figure that cannot be confidently verified. This is explained further in the following document. There is a glossary of terms at the bottom of this document, for further clarification.

It is important to note: it can be reasonably assumed that most survivors of paralytic polio, and many of those who had non-paralytic polio, will be at risk of experiencing the Late Effects of Polio^{1,2}.

Polio Australia's previous position paper

In 2014, Polio Australia released a Position Paper³ estimating that there are 400,000 polio survivors living in Australia. This figure included all those who had been diagnosed as contracting paralytic polio (estimates range from 23,000 to 73,750^{4,5}) as well as those who were diagnosed as contracting non-paralytic polio, and those who were never diagnosed (many of whom were asymptomatic). However, the estimate had the unintended consequence of leading many to infer that 400,000 people are living with the Late Effects of Polio.

Considerations in estimating numbers

Considerations in developing an accurate and specific estimate of polio survivors living in Australia who may be experiencing Late Effects of Polio include:

- Paralytic polio is only a small percentage of polio cases; some people who were not diagnosed with paralytic polio may still experience the Late Effects of Polio.⁶
- Misdiagnosis at the time of contracting polio.
- Under-reporting of polio cases.

¹ Bruno, R. (2000). *Paralytic vs. "nonparalytic" polio: distinction without a difference?*, American Journal of Physical Medicine and Rehabilitation.

² Matyja, E. (2012). *Post-polio syndrome. Part I. The "legacy" of forgotten disease, challenges for professionals and polio survivors*, Neurologia i Neurochirurgia Polska.

³ Polio Australia Position Paper (2014), *Numbers of polio survivors living in Australia*.

⁴ Jones, K. M., Balalla, S., Theadom, A., Jackman, G., & Feigin, V. L. (2017). *A systematic review of the worldwide prevalence of survivors of poliomyelitis reported in 31 studies*, BMJ open.

⁵ The Department of Health (2003), *Notifiable diseases surveillance 1917-1991*.

⁶ Brauer, P. (2011). *Aspects of the Post-Polio Syndrome*, Bielefeld, Germany: Polio Selbsthilfe e.V.

- Diagnosis not recorded retrospectively (both for cases within Australia and for migrants entering Australia).
- Unknown rates of attrition from death or emigration.
- New polio survivors migrating to Australia from countries where polio is still endemic, or was eradicated more recently.

Australian Polio Register

Polio Australia has established a register of polio survivors living in Australia, known as the [Australian Polio Register](#). Registration numbers rely on people knowing about Polio Australia and the *Register*, knowing about their polio history, and adding their own name to it. Hence we are aware that the Register represents only a small percentage of Australia's post-polio population and it should therefore be viewed as simply providing one part of the overall picture. Even in its current form, however, the Register provides important demographic data and statistics that would otherwise be unavailable and will have historical significance into the future.

Glossary of terms

Paralytic polio	A case of polio infection involving sufficient motor neurone damage to cause loss of muscle function (and/or problems with breathing, speech or swallowing) – affects less than 1% of people infected with Poliovirus.
Non-paralytic polio	Polio infection that does not cause paralysis (however sub-clinical motor neurone damage is present in 1-5% of cases of polio infection).
Late Effects of Polio	An umbrella term which includes the onset, or worsening of weakness, fatigue and pain, and a range of biomechanical symptoms such as osteoporosis, scoliosis, joint pain, tendonitis and bursitis.
Post Polio Syndrome	A sub-category of the Late Effects of Polio. It is a diagnosable neurological condition, and symptoms include muscle weakness and atrophy, fatigue, muscle and joint pain, and difficulties with breathing and swallowing.