



Spleen Australia

Annual Report for 2024

1. Introduction

It is a privilege to present Spleen Australia's first annual report—representing a dedicated service committed to improving the health of individuals living with asplenia or hyposplenism. We are committed to reducing preventable infections and empowering people without a functioning spleen to live healthier lives. This report outlines Spleen Australia's operational performance and Quality Account for the period 1 January 2023 to 31st December 2024.

Since its inception in 2003, Spleen Australia has grown from a Victorian initiative into a national service supporting over 15,000 patients across Victoria, Tasmania, Queensland, and Western Australia. Based within the Department of Infectious Diseases at Alfred Health, we continue to support hospital specialists, GPs, and patients through evidence-based care.

We honour the legacy of Penny Jones, our founding manager, whose visionary leadership laid the foundation for our work. Penny stepped down this year after a long illness, and her impact continues to guide us.

2024 has marked a year of renewal and progress. Following Penny Jones's departure, Sharon O'Brien has been acting in the manager role. Since then, we've expanded our governance structures, strengthened collaborations with clinical and academic experts, and renewed our commitment to evidence-based care with a national focus. We're actively engaging with stakeholders across state health departments and general practice to raise awareness, improve access, and ensure consistent standards of care across all regions.

A major milestone this year was the formation of a Steering Committee in Western Australia—a multidisciplinary group providing strategic oversight to support sustainable service delivery in the west.

Looking ahead, we remain focused on strengthening partnerships, expanding our reach, increasing awareness with education, and advocacy. We are deeply grateful to our partners, clinicians, supporters, and above all, the patients and families who inspire our work every day.



2. Overview of Service

Asplenia and hyposplenism present significant health risks including severe bacterial infections and risk of sepsis leading to hospitalisation and an increased risk of death. Spleen Australia offers a patient-centred approach that has been proven to be effective, with a **69% reduction in infection risk** for registered patients ⁽¹⁾, demonstrating its protection in this vulnerable population.

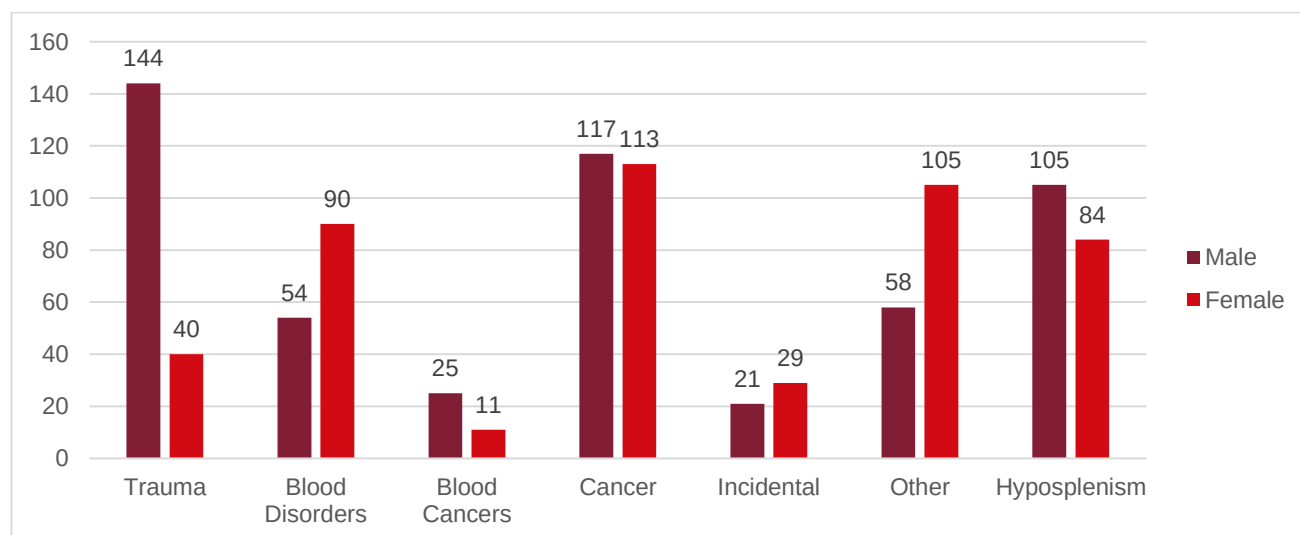
Spleen Australia's services have been shown to be cost effective as confirmed in two independent studies⁽²⁾. Joining Spleen Australia also provides access to extensive expertise and specialist knowledge developed within the service. The service supports both paediatric and adult patients and offers individualised vaccination and antibiotic plans.

People who have undergone splenectomy or have reduced splenic function face a significant health risk:

- **50x higher risk of sepsis** compared to the general population
- **5% lifetime risk** of admission to ICU with Overwhelming Post-Splenectomy Infection (OPSI).
- **200x higher risk of death** from sepsis compared to those with an adequate functioning spleen ⁽³⁾.

The diverse underlying conditions leading to registration with Spleen Australia, outlined in Figure 1, underscores the need for collaboration across multiple specialties.

Figure 1 – Underlying Conditions for Registration to Spleen Australia in 2024 (n=996)



Trauma can be car accidents, assaults, falls etc

Blood disorders are blood disorder that affects blood cells and platelets and can cause issues with bleeding

Blood malignancy is cancers of the blood like lymphoma

Cancer can be malignant tumours in the abdomen e.g. bowel, stomach, pancreatic etc

Incidental - when the splenectomy is not planned and occurs at the time of another operation

Other is pancreatic disorders, spontaneous rupture, abscess, cysts, benign tumours

Hyposplenism is when the spleen is non-functioning or if you were born without a spleen

Figure 2 – Total Breakdown of Registrations – Total 15056

Active	Deceased	Inactive	Pending	Incomplete
12541	1630	575	201	65

Active –Registration completed – sent information, antibiotic and vaccine plan sent, educated

Inactive - An individual lost to follow-up or someone not eligible for service e.g. Splenic Artery Embolisation

Pending - Awaiting splenectomy or someone from a non-eligible state who wishes to remain on the database

Incomplete - registered individual requiring further follow up

Figure 3 – Registrations to Spleen Australia per State, Adults and Paediatrics

The number of registrations each year with a breakdown by state and Figure 4 breaks it down further into each month during 2024. It highlights the ongoing demand in established states such as Victoria and Queensland and the work that is invested in promoting the service maintaining the relationship with key referring clinicians. It demonstrates the work that needs to go into raising awareness in states which have joined in recent years e.g. WA into its second year of funding.

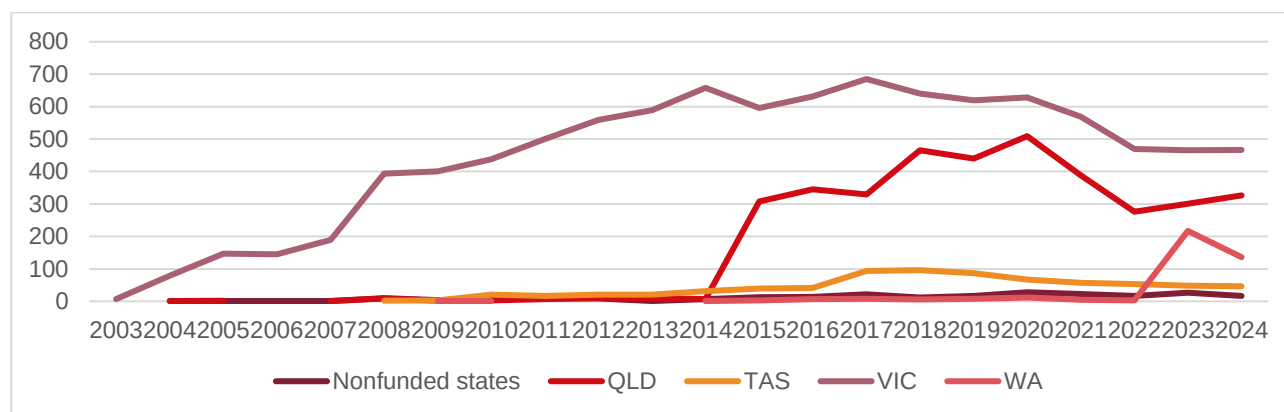


Figure 4 – Monthly Registration Rate per State in 2024

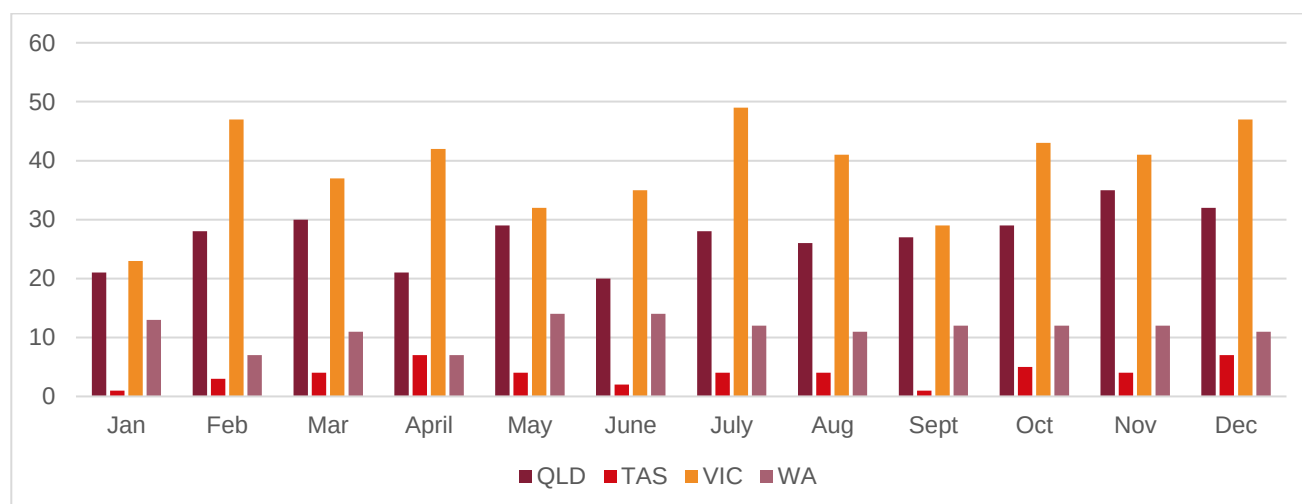


Figure 5 – The number of registrations per state over past 3 years

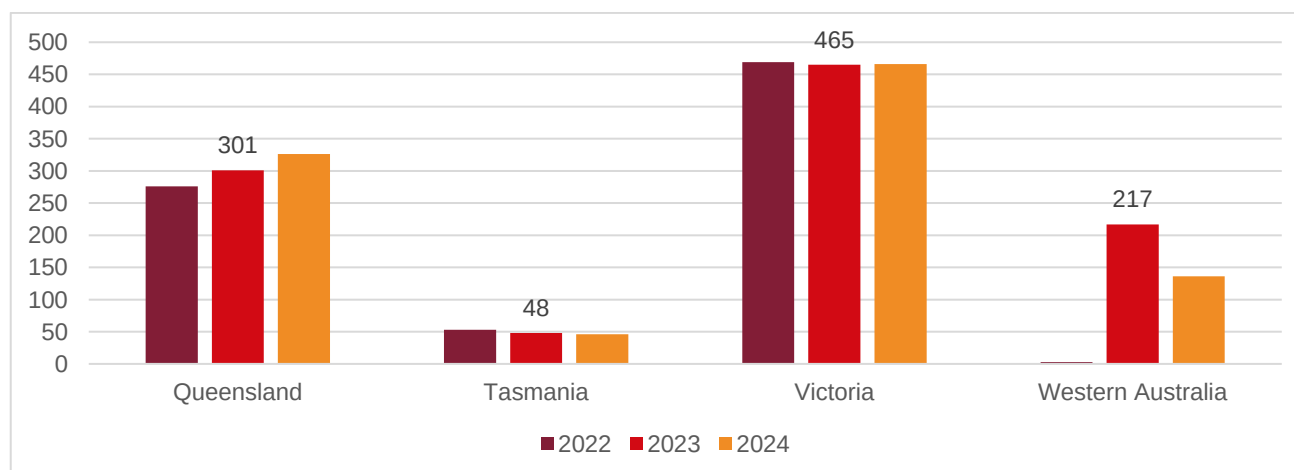


Figure 6 – The number of initial reports completed over the past 3 years from 2022-2024

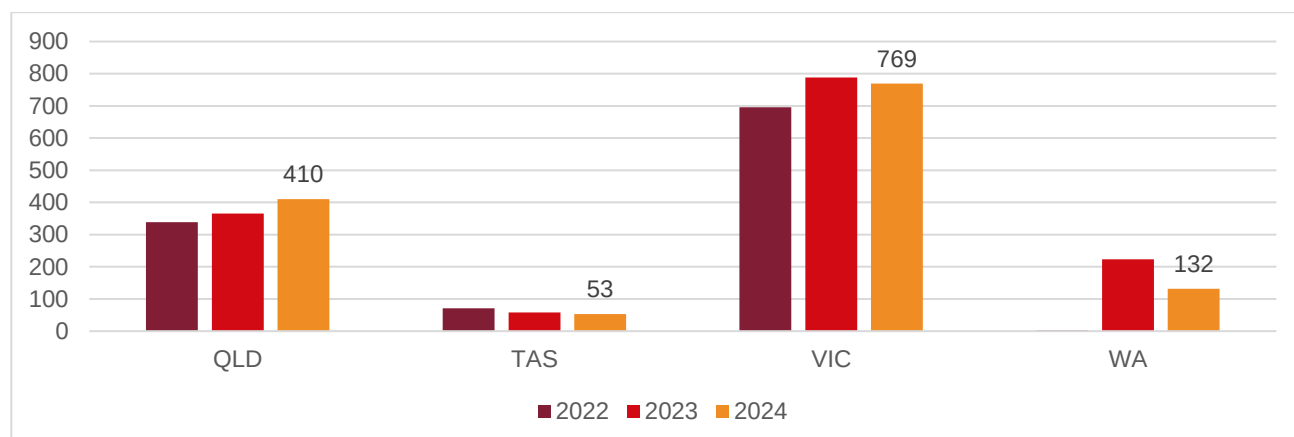


Figure 7 – Updated Reports 2022-2024, if > 1 year since last report

Spleen Australia encourages all registered patients to contact us every 5 years to receive an updated vaccination and antibiotic plan. This process helps ensure continued protection over time. The graph below demonstrates the number of updated reports each year from 2022-2024. As expected, the number of updates in WA remains low, given the service was only recently established in the state.

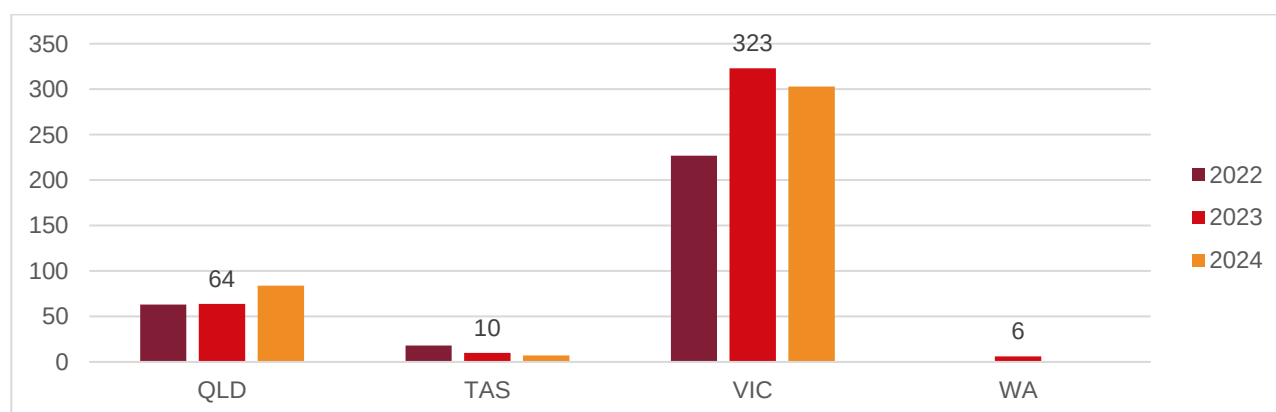


Figure 8 – Age and gender at time of registration

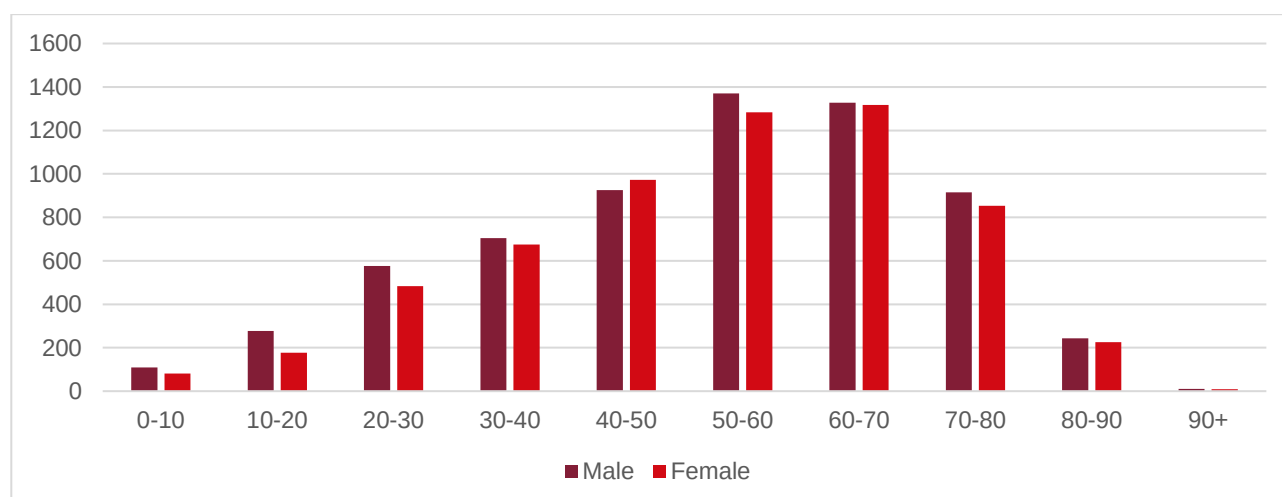


Figure 9 – Aboriginal and Torres Strait Islanders Registrations

The registration data indicates that Aboriginal and Torres Strait Islander individuals account for 2% of registrations. However, this group represents 3.8% of the Australian population, highlighting a potential underrepresentation in the registration process.

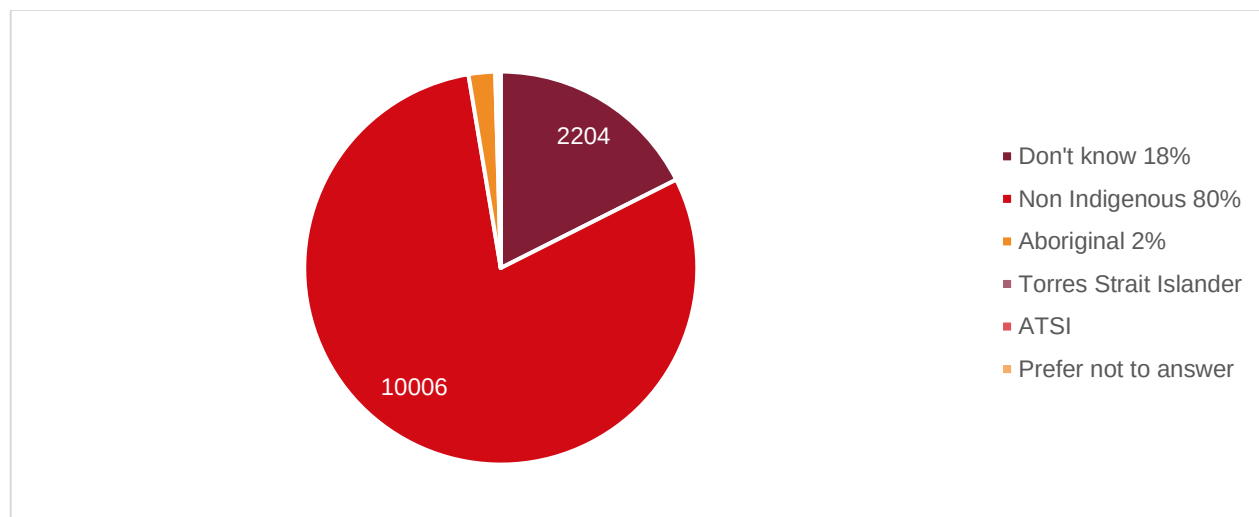
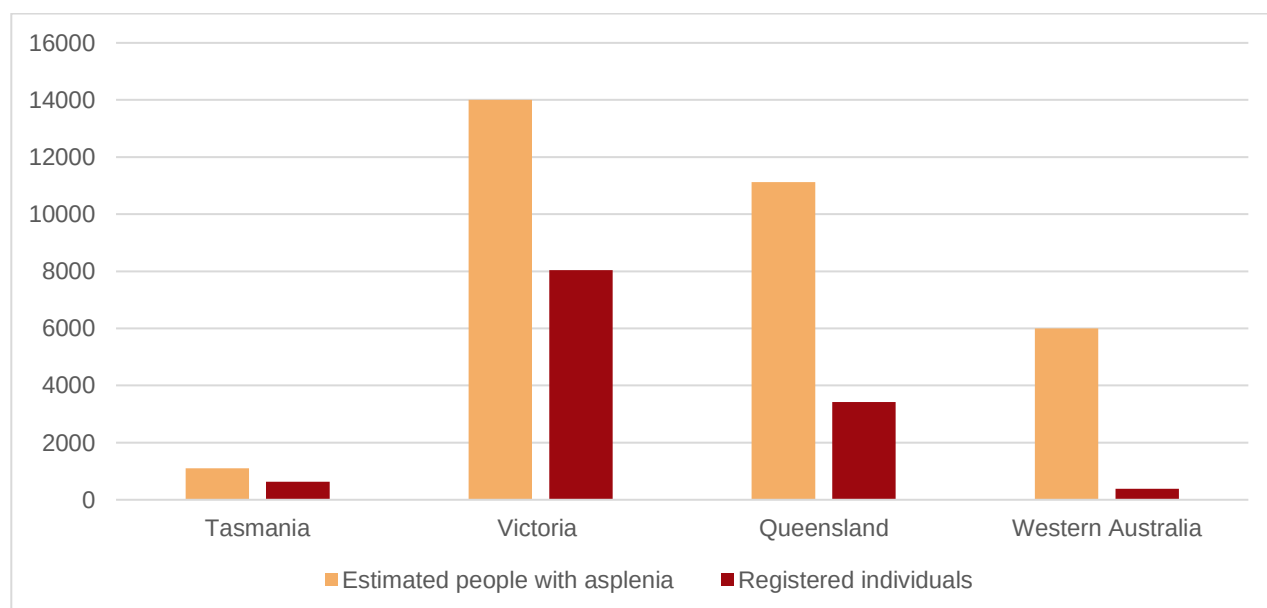


Figure 10 – Estimated Number of Individuals with Asplenia per State (0.2% population)

It is estimated that 0.1–0.3% of individuals have asplenia. This graph illustrates the estimated number of individuals with asplenia compared to those who are registered, highlighting a potential gap in registration.



3. Support and Services Provided

3.1.1 Medical Expertise

Prof. Denis Spelman an Infectious Diseases Physician at Alfred Health was the founder of Spleen Australia. Prof. Spelman is a clinical microbiologist and has extensive experience in infection prevention and antibiotic resistance he has led multiple research projects and publications about asplenia and hyposplenism. However, he is presently on extended leave. Dr Nenad Maccesic an Infectious Diseases Physician and Researcher at Alfred Health and Monash University is currently acting as our medical lead. Dr Maccesic cares for immunocompromised patients and has led multiple international research projects in antimicrobial resistance.

3.1.2 Nursing Expertise

The service is supported by five experienced clinical nurse consultants all with qualifications as nurse immunisers and an administrative support officer. The team have different clinical backgrounds in Trauma, ICU, Infectious Diseases, Research and General Surgical/Burns nursing.

3.1.2 Services Provided

Figure 11 –The number of contacts in 2024 is categorised by type and the individual or group responsible. This breakdown provides an overview of engagement across different contact types and contributors.

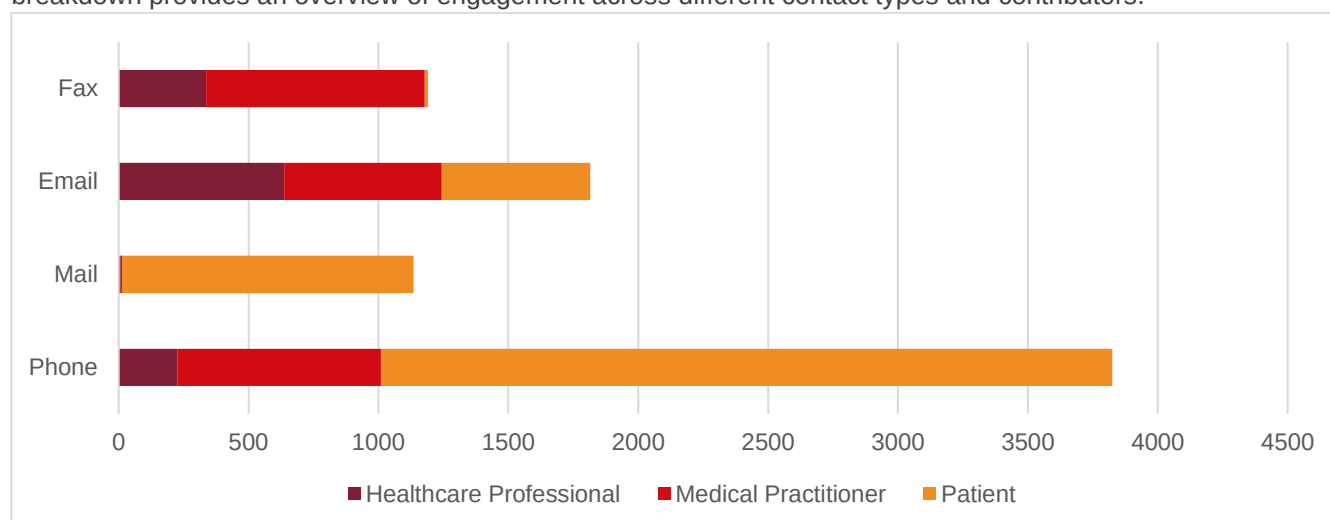
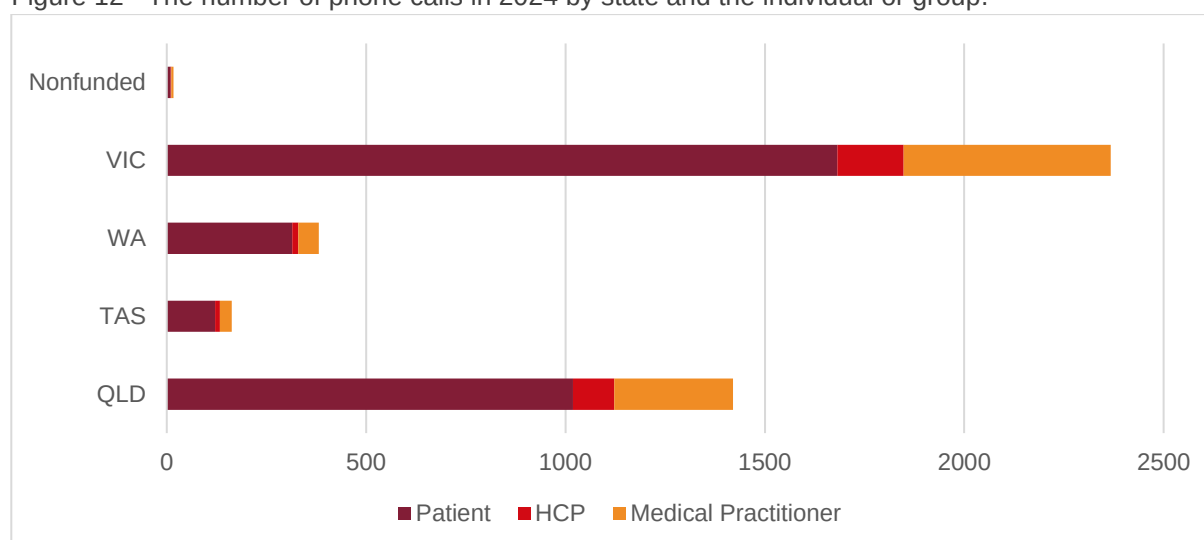


Figure 12 - The number of phone calls in 2024 by state and the individual or group.



4. Highlights For Service in 2024

4.1 - Thank you, Penny Jones!

Penny has been the driving force behind the creation of the Spleen Registry at Alfred Health in 2003, working alongside Professor Denis Spelman. What began as a small initiative with one patient has grown into Spleen Australia, now supporting over 15,000 patients across Victoria, Tasmania, Queensland and Western Australia.

For the past 22 years, Penny has led the way, building strong partnerships with patients, health departments, public health experts and politicians. We thank her for her dedication and effort; Spleen Australia has made a lasting difference in the lives of individuals with asplenia.



While we are saddened by Penny's departure, we are deeply grateful for her hard work, passion and the positive impact she's had. Penny, you've left an incredible legacy, and we cannot thank you enough for everything you have done!

4.2 - Establishment of the New Steering Committee in Western Australia

We are proud to announce the establishment of a new steering committee in Western Australia. This committee will serve as an advisory and governance body, providing strategic guidance and oversight to ensure the success and sustainability of our initiatives.

4.3 - Representation at the CDIC Conference

Penny Jones and Sharon O'Brien represented Spleen Australia at the CDIC Conference in Brisbane, presenting on *Shingles in People with Non-functioning Spleens*. Additionally, they displayed a poster titled *Overall Health of Registered Patients During the COVID-19 Pandemic*. These contributions emphasise Spleen Australia's commitment to addressing key health challenges and supporting the wellbeing of individuals living with asplenia or hyposplenism.

4.4 - Hospital Visits Following the Conference

After the conference we utilised our time in Brisbane and visited some of the hospitals and presented to medical and nursing staff improving awareness of risks of asplenia and preventative strategies at:

- Queensland Children's Hospital
- Princess Alexandra Hospital
- Sunshine Coast University Hospital

4.5 - Promoting Awareness of Spleen Australia

We are actively promoting awareness of Spleen Australia through various publications:

- Featuring updates in immunisation newsletters across Queensland, Victoria, Tasmania and Western Australia.
- Sharing a patient case study in GP newsletters via Primary Health Networks in funded states.

These initiatives aim to enhance knowledge and engagement with healthcare providers and the broader community, ensuring improved support for individuals living without a functioning spleen.

4.6 - Educational Initiatives

Spleen Australia was proud to host a webinar in collaboration with Pancare, an organisation dedicated to supporting individuals with pancreatic cancer. Additionally, an online education session was organised with the Queensland Infection Prevention and Control Unit to improve understanding and strategies related to infection prevention for those with asplenia. These initiatives reflect our ongoing commitment to education and collaboration to improve the health outcomes for individuals living without a functioning spleen.

4.7 - Welcoming Anne Paterson to the Team

We are pleased to welcome Anne Paterson to the Spleen Australia team. Anne joins us from the Infectious Diseases Research Department and is an experienced Immunisation Nurse. We are excited to have her on board and look forward to the contributions she will make to our team.

5. Testimonials

In 2023 our service started in WA, we had a lot of positive feedback; below this is an example of some of the letters we received from patients. We appreciate all feedback (negative and positive) to help improve our service and to provide much needed support for our continued funding from state departments.

"I would like you to know that your organisation does a fantastic job in keeping me informed about living without a spleen. My conversations with you have always been very helpful and informative and your ongoing support is greatly appreciated - always there to answer any concerns I may have as well as keeping my doctor informed which is important to me and I'm sure to many others. Thank you so much for all you do - it's a great comfort knowing you are just a call away whenever I have any concerns". JT

"Spleen Australia has provided a vital line of support for people like me who have ended up with no spleen and quite often full of anxiety with how to navigate life without one. The information Spleen Australia has provided me in the past and continue to keep me updated is crucial for me and my mental health. I feel that if I ever require clarification on immunisation matters or other health related concerns because of the spleen, they are always available". DD

"Doctors haven't been great at letting me know when my vaccines are due and with your help it has kept me informed and kept me up to date with vaccines. You have provided me with a lot of info and my spleen medical card which the doctors didn't even know about". JS

"Doctors have so many things they need to be across now days. For every new doctor I meet I have to continually questions things or remind them I don't have a spleen". MF

"I was only given a small amount of information when I left the outpatient clinic at my children's hospital, (PMH at the time) as a young adult, when it was finally time for me to leave this part of my care plan. It turns out there were a lot of vaccinations I required to be fully protected and at the age of 51, it has taken this long to know, thanks to your team as prior to this WA were not eligible for your service. I feel it's really important for asplenia patients to be made aware of what's required to protect us, and I feel relieved to be part of Spleen Australia finally, it's been a long time coming for West Australians so thank you for allowing me to be part of this". LP

"As someone who has been without a spleen for over 40 years, your assistance in managing my health and well-being has been nothing short of amazing. I must admit, I had no idea just how vulnerable and immunocompromised I was until I started receiving your care and guidance. Your expertise and dedication have been invaluable in helping me better understand and manage my health, and for that, I am deeply grateful". SW



Spleen Australia team pictured from left: Sharon O'Brien, Sharon Willems, Ambler Plumley, Ella Brown, Anne Paterson (absent Megan Harvey, Dr Nenad Macesic)

6. Research

Our vision is to support and promote research that advances the understanding, prevention, and management of infections, vaccination strategies, antibiotic protocols and other health risks faced by people without a functioning spleen.

We are actively partnering as consumer representatives and supporting participant recruitment in several research projects, all of which have received ethics approval through their respective universities, hospitals, and research institutions. Current projects include:

- Investigation into Colonoscopy as a Precipitating Cause of Splenectomy
- Spleen Salvage Procedures and their impact on immune function
- Impact of COVID-19 on Registrants of Spleen Australia
- PROPHECY Study – A national study examining immune responses to COVID-19 in paediatric and adult immunocompromised populations.

Spleen Australia has actively contributed to the development and refinement of key national resources, including the Australian Immunisation Handbook and the Therapeutic Guidelines: Antibiotics. These contributions ensure that evidence-based recommendations for the prevention of overwhelming post-splenectomy infection (OPSI) remain current, practical and responsive to the evolving needs of this vulnerable population.

Independent evaluations have confirmed the value and impact of Spleen Australia's model of care. These studies demonstrate that our service is not only clinically effective but also cost-effective, preventing severe infections and associated hospitalisations through proactive vaccination, education and long-term follow up. The findings reinforce the importance of investing in coordinated care for people living without a functioning spleen and provide a strong foundation for sustained funding and national expansion.

7. Future Directions

In the coming year, we are focused on expanding the reach of our service to ensure it is available to all individuals living without a functioning spleen across Australia. Our primary goals include extending the service to states and territories not yet fully integrated into our program and deepening our engagement in recently joined regions, particularly Western Australia. This will involve building strong partnerships with local health networks, clinicians, and community organisations to increase awareness, support patient registration and ensure consistent delivery of care.

We plan to modernise and broaden our digital offerings, including website upgrades and interactive tools to support patient engagement and education.

We will continue to advocate at both state and national levels to raise the profile of asplenia and hyposplenism, emphasising the importance of preventive care, appropriate vaccination and equitable access to services for all Australians.

8. References

1. "A registry for patients with Asplenia/Hyposplenism reduces the risk of infections with encapsulated organisms." Clinical Infectious Diseases – 2018. Alicia Arnott, Penelope Jones, Lucinda Franklin, Denis Spelman, Karin Leder, Allen Cheng
2. "Initial modelling and updates on cost effectiveness from the first 10 years of a spleen registry". Aust N Z J Public Health. 2018 Oct; 42(5):463-466. Sarah Luu, Penelope Jones, Ian Woolley, Denis Spelman, Lisa Gold
3. "Asplenia" National Library of Medicine – 2024. Damilola Ashorbi, Roberto Fernandez