

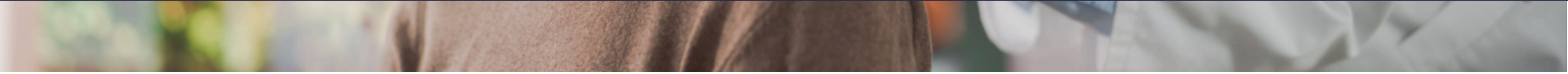


Australasian
Dermatology
Registry

October | 2024

NEWSLETTER

Psoriasis Edition



- Welcome message
- Meet the psoriasis team
- Key statistics
- Research projects
- Presentations and publications
- Patient portal
- Clinician portal
- Continued professional development
- Acknowledgements

WELCOME

By A/Prof Chris Baker

Co-Convenor of the Australasian Dermatology Registry, Co-Chair of the Psoriasis Scientific Advisory Committee, and Director of Dermatology at St. Vincent's Hospital Melbourne

As we venture into October, we're excited to welcome you to the special second edition of the Australasian Dermatology Registry newsletter, on this occasion focused on psoriasis.

The Australasian Dermatology Registry (ADR) is a reimagining and expansion of the Australasian Psoriasis Registry (APR) which successfully recruited over 2,500 patients from 109 clinics across Australia and New Zealand. In an advancement on its predecessor, the ADR is designed to minimise and streamline data entry through user-friendly patient and clinician portals, and provide real-time reporting to clinics.

Treatment of psoriasis has seen significant advances in the last decade with the addition and refinement of biologic therapies, the introduction of new oral advanced targeted therapies, and new formulations of topical treatment, offering improved safety profiles and focusing on long-term disease management and gains in patient quality of life. With these advancements, local real-world evidence has become increasingly vital for guiding treatment decisions and improving patient outcomes. This is where the ADR plays a crucial role.



WELCOME cont.

By A/Prof Chris Baker

By capturing comprehensive longitudinal data from clinics across Australasia, the ADR provides dermatologists with invaluable local real-world evidence to inform clinical decision-making and to facilitate advocacy for our patients.

In addition to monitoring and evaluating current and emerging treatments, the ADR is a research platform offering de-identified data access to all participating clinics. In this edition of our newsletter, we highlight some of the exciting research studies currently utilising ADR data.

As participation in the registry continues to grow, so does our capacity to tackle meaningful research questions and enhance patient care. We encourage all dermatologists to explore the ADR and discover how even a small contribution can make a large impact on the quality of care we provide to our patients.

MEET THE TEAM

Each of our Scientific Advisory Committees play a pivotal role in shaping and guiding the registry. These dedicated groups of experts have helped to design the registry, determine what data to collect, and set reporting requirements. As the registry grows, the committees will continue to be involved in evaluating emerging data, prioritising research, reviewing research protocols, handling data access requests and overseeing publications and presentations.

Psoriasis Scientific Advisory Committee

In this edition of our newsletter, we are excited to introduce our Psoriasis Scientific Advisory Committee. We deeply appreciate their insights and recommendations, which have been crucial for guiding our collective efforts and advancing psoriasis research in Australia.



A/Prof Chris Baker
Co-Chairperson,
Dermatologist - VIC



A/Prof Peter Foley
Co-Chairperson,
Dermatologist - VIC



Ms Sue Anderson
Dermatology Nurse - VIC



A/Prof Kurt Gebauer
Dermatologist - WA



Dr Monisha Gupta
Dermatologist - NSW



Prof Johannes Kern
Dermatologist - VIC



A/Prof Patricia Lowe
Dermatologist - NSW



A/Prof Gillian Marshman
Dermatologist - SA



Mr Murray Turner
Consumer Representative



Dr Jason Wu
Dermatologist - QLD



MEET THE TEAM cont.

Meet Our Psoriasis Consumer Representative

Each of the Scientific Advisory Committees includes a consumer representative. These consumers play an important role in ensuring that research efforts align with patient needs and perspectives, enhancing the relevance and impact of the studies conducted.



Mr Murray Turner
Consumer Representative

The Australian Dermatology Registry - A Patient Perspective

By Murray Turner, CEO of Psoriasis Australia

Being a patient diagnosed with psoriasis and CEO of Psoriasis Australia, I am often frustrated with the lack of accurate, comprehensive and up-to-date information on psoriasis in Australia. Far too often I am unable to provide key decision makers with a true snapshot of the burden of psoriasis in Australia. This therefore has an impact on our advocacy efforts in gaining access to new treatments sooner or lobbying for more dermatologists.

The Australian Dermatology Registry (ADR) is an important initiative that will improve the care and treatment of patients with psoriasis for several reasons. It will:

Improve Access to Care - it will allow patients to experience more personalised care due to the ability to track the effectiveness of various treatments over time. By utilising data from the registry, healthcare professionals can more accurately identify which treatments are likely to be most effective based on a patient's specific characteristics, therefore, reducing the time spent on ineffective therapies.

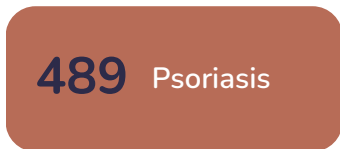
Support Research and Policy Development - it will provide researchers and policymakers with access to up-to-date and reliable data, that can be used to inform healthcare policies, allocate resources, and guide research efforts.

Raise Awareness - the centralised data repository will allow Psoriasis Australia to better inform the public about the burden of psoriasis and associated comorbidities, therefore reducing the stigma and promoting a better understanding of the disease.

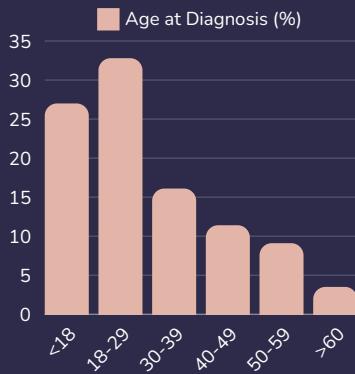
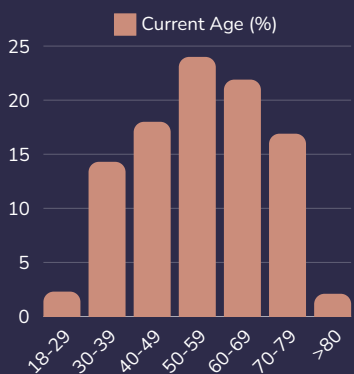
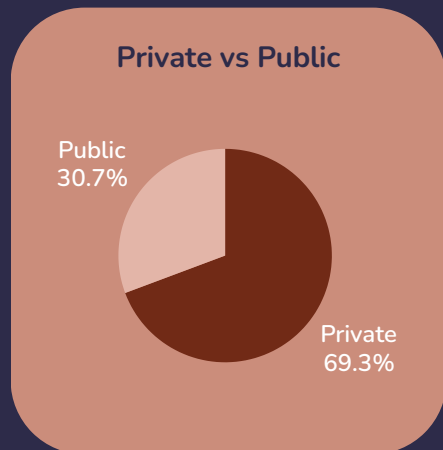
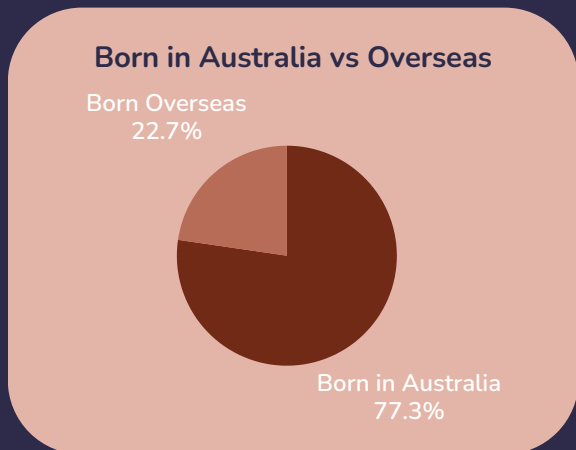
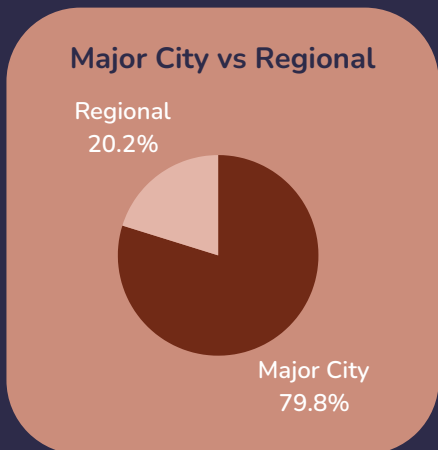
Overall, the ADR is a critical initiative for improving the understanding of psoriasis and the burden of the disease on those in Australia. If your clinic has not yet registered to be part of the registry, I implore you to reach out to the ADR, so you and your patients can help improve the care, treatment and lives of those impacted by psoriasis.

KEY STATISTICS

as of 1 October | 2024



Psoriasis Statistics



Gender



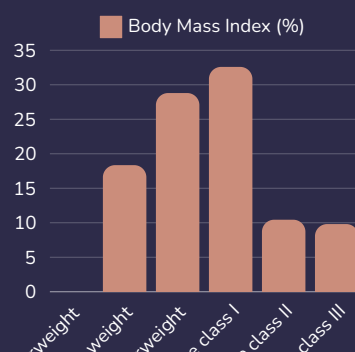
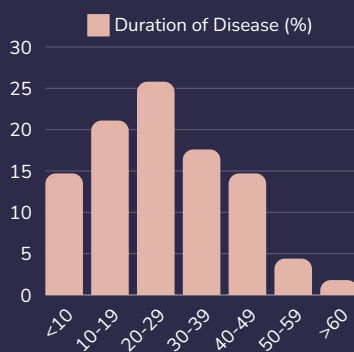
67.1%

Male



32.9%

Female



Psoriatic Arthritis



29.1%

Yes



70.9%

No

Biologic Experienced vs Biologic Naïve



80.3%

Biologic



19.7%

Biologic Naive



RESEARCH PROJECTS

The Australasian Dermatology Registry has been designed to support the use of registry data for research studies. Clinics contributing participants and data to the registry can request access to de-identified data for their own research studies through the data access policy and request forms. Requests to access de-identified data are reviewed by the disease specific Scientific Advisory Committee to ensure that projects are unique, and the methodology is robust before the data are released.

Current Projects

Biologic efficacy in treatment of psoriasis as determined by the location of disease

The introduction of biologics in the treatment of psoriasis has been life-changing for many patients. With a wide range of biologics available on the market, is there a benefit to selecting one over another? One consideration in choosing which biologic to prescribe is the location of the disease.

The registry is analysing the efficacy of a participant's first biologic (e.g., targeting TNF, IL-17, or IL-23) based on the individual's disease location (e.g., torso, upper limbs, hands, feet) to identify if there is an advantage in prescribing one category of biologic over others based on site(s) involved. Determining if there is variation in clinical outcomes will enable clinicians to make informed treatment decisions and support patients in receiving the best care.

The results of this study will be submitted for presentation at the Brisbane ACD ASM in 2025.

Funding to support this study was provided through a grant from The F & E Bauer Foundation

Drug survival of Deucravacitinib in treating psoriasis

Deucravacitinib is an oral selective tyrosine kinase 2 (TYK2) inhibitor used in the treatment of moderate to severe plaque psoriasis. Phase 3 clinical trial data (POETYK PSO-1 and POETYK PSO-2) have found Deucravacitinib to be effective and safe, but limited information is available regarding its use in real-world patients, particularly those in Australia.

To determine if the drug survival rate and reasons for ceasing treatment in real-world Australian patients are consistent with those in clinical trial data registry participants, an analysis will be conducted. This analysis will examine the drug survival rate for the first two years of treatment, reasons for treatment cessation (e.g., lack/loss of response, adverse reactions), and factors that may affect drug survival (e.g., age, gender, comorbidities, smoking status, alcohol use, BMI). The results will be compared with the POETYK PSO-1 and POETYK PSO-2 trial findings.

Preliminary results of this study are expected to be available in January 2027.

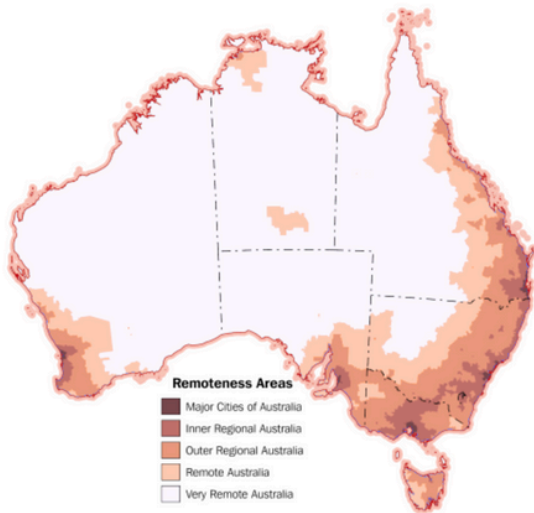
Funding to support the development of this study, including data cleaning and analysis, has been provided by Bristol Myers Squibb.





RESEARCH PROJECTS cont.

Upcoming Projects



Comparison of regional and metropolitan patients with psoriasis to identify variation in demographics, treatment and outcomes

In Australia, 6% of dermatologists practice in regional and remote areas, despite 28% of Australians living in these regions. This discrepancy results in limited access to services for patients, who may need to travel to metropolitan areas for treatment. The impact of reduced access on disease severity at presentation, treatment availability, distance travelled to see a dermatologist, and the effects on quality of life and mental health due to these chronic diseases has not been previously reported.

The ADR will compare patients with psoriasis residing in regional and rural areas with those living in major cities to identify variations in demographics, lifestyle factors, mental health, quality of life, disease severity, treatment, and outcomes. Comparing differences between participants in major cities and those in regional or rural areas will help identify areas in need of support.

Effect of biologic treatment on cancer incidence

The evidence regarding whether treatment with biologic agents increases the risk of cancer remains inconclusive. Some studies suggest a potential association between biologic therapies and a higher incidence of cancer, while others find no such link. The variability in study results underscores the need for further investigation to clarify this relationship.

To address this uncertainty, data from the Australian Data Registry (ADR) will be analysed to evaluate the potential correlation between biologic treatments and cancer incidence in the Australian cohort. This analysis aims to provide more definitive insights by examining cancer rates among patients receiving biologic therapies compared to those not on such treatments. By focusing on this specific population, the study hopes to shed light on whether these drugs pose a significant risk and help guide future clinical decisions.

If you are interested in requesting data for your study or would like to contribute data from your clinic to support local dermatology research, please contact the registry staff at:

registry@australasiandermatology
registry.org.au

or (03) 9623 9470

LEARN MORE



PRESENTATIONS AND PUBLICATIONS

Previous

The Australasian College of Dermatologists 56th Annual Scientific Meeting
11-13 May 2024 | Perth, WA

Registrar Presentations

- Drug survival of biological therapies in smokers and non-smokers with psoriasis: A retrospective cohort study using data from the Australasian Psoriasis Registry. - Dr Ferial May [DOWNLOAD PDF](#)
- Real-world evidence for Ustekinumab treatment of severe psoriasis: Drug survival and efficacy results from the Australasian Psoriasis Registry. - Dr Jacqueline Kim Nguyen [DOWNLOAD PDF](#)

Poster

- Hidradenitis Suppurativa dataset within the Australasian Dermatology Registry [DOWNLOAD PDF](#)

The Australasian College of Dermatologists 8th Rural Dermatology Meeting
6-8 September 2024 | Hobart, TAS

Presentation

- Rural patients within the Australasian Dermatology Registry - A/Prof Peter Foley [DOWNLOAD PDF](#)



Upcoming

USING THE AUSTRALASIAN DERMATOLOGY REGISTRY FOR RESEARCH

with A/Prof Peter Foley, A/Prof Gayle Ross and Dr Jason Wu

MONDAY 11TH NOVEMBER 2024 AT 7:00PM AEST VIA ZOOM

Real-world dermatology research is crucial for improving patient care by enhancing the understanding of skin disease, refining treatment strategies, monitoring of current and emerging treatment, bridging gaps in evidence, and supporting regulatory decisions.

The Australasian Dermatology Registry encourages research by providing de-identified registry data to any participating clinician through the data access policy. This presentation will highlight the data available, the process to access registry data, and highlight current and future research studies.



[CLICK HERE TO REGISTER](#)



PATIENT PORTAL

The Australasian Dermatology Registry (ADR) Patient Portal is an innovative platform designed to streamline the way we deliver participant information, collect consent, and manage participant data, ultimately leading to improved outcomes.

What is the Patient Portal?

The ADR Patient Portal is a secure, user-friendly digital platform that allows participants to input and update their own medical information. By scanning a QR code, participants can effortlessly access the participant information, consent form, and condition specific questionnaires from their smartphones or other devices. This easy-to-navigate system is a leap forward in integrating participant consent and real-time data into dermatological research and practice.

Benefits of the Portal

Enhanced Data Accuracy and Completeness:

- The Patient Portal enables participants to provide accurate and comprehensive details directly, minimising discrepancies, and ensuring that the data used in their care are as precise as possible.

Streamlined Data Collection:

- Traditionally, collecting participant data relied on time-consuming manual entry by clinical staff of the medical history obtained from the patient. By having the patient enter their own data, the data entry required by clinical staff is minimised and can easily be completed during the consultation.

Recruiting Participants via the Portal

Recruiting participants with the Patient Portal is simple. Patients can access it by scanning a QR code provided during their clinic visit or included in the ADR participant brochure. Once the QR code is scanned, participants will be guided through a straightforward consent process and start inputting their data.



Security and Privacy

We understand that security and privacy are paramount when it comes to handling personal health information. The ADR Patient Portal employs the highest standard of encryption and data protection measures to ensure that all patient information remains confidential and secure.

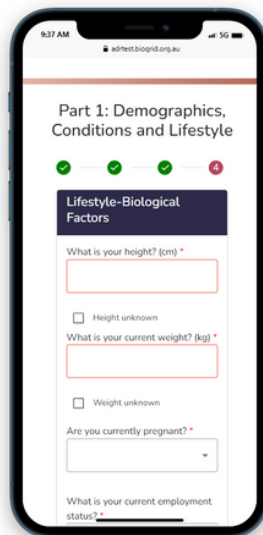
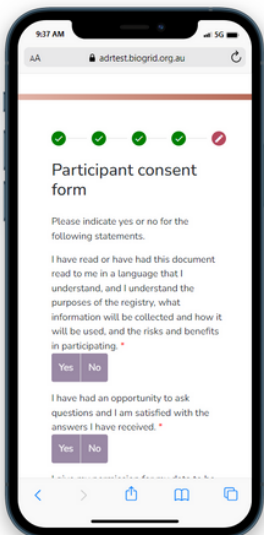
Get Involved

We are thrilled about the potential of this new tool and look forward to its positive impact on patient care and research.

For more information on how to register as a participating site, please email:

registry@australasiadermatologyregistry.org.au.

Together, we are shaping the future of dermatology — one scan at a time.



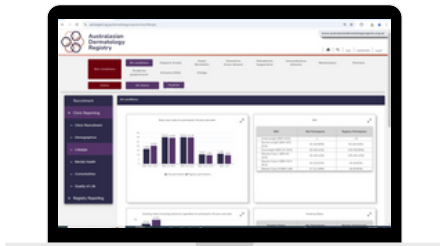
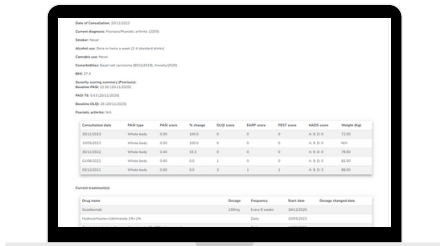


CLINICIAN PORTAL

The Australasian Dermatology Registry (ADR) Clinician Portal is more than just a data repository; it's a tool that empowers you to enhance patient care and clinic performance. By providing easy access to patient, clinic and registry data, the portal supports more precise clinic auditing, and improved patient outcomes.

Accessing the Portal

The ADR Clinician Portal is a web-based application, ensuring that you can access it from any device with an internet connection. Simply navigate to the portal via the ADR website and log in with your secure credentials. If you are new to the portal, our easy-to-follow onboarding guide will get you started in no time.



Benefits

- **Patient Summary Tables:** Gain instant access to detailed patient summaries, allowing you to view critical information at a glance. The summary tables offer a holistic view of each patient's history, treatment progress, and outcomes, enabling more informed decision-making and personalised care.
- **Clinic Data:** Track and analyse your clinic with access to a range of metrics. The clinic reporting section provides insights into patient demographics and management. Use these insights to identify trends, reflect on performance, optimise resource allocation, and improve your clinic services.
- **Registry Data:** Explore comprehensive registry data to benchmark against national standards. The registry reporting section is invaluable for understanding broader dermatological trends, contributing to research, and ensuring that your practice aligns with best practices and guidelines.
- **Category 2 and 3 CPD:** The time you spend reviewing reports can be claimed as Continued Professional Development (CPD) with the Australasian College of Dermatologists. This is a great way to meet your CPD requirements while directly contributing to improved patient care and clinic performance. You can read more about how to claim CPD on page 10.

Support and Training

Our dedicated support team is here to assist with any questions or technical issues you might encounter. Additionally, we offer ongoing training sessions and resources to ensure you, and your team, are making the most of the portal's features.

Get Involved

We encourage you to actively use the Clinician Portal and provide feedback. Your input is crucial for ongoing improvements and ensuring that the portal meets the evolving needs of the dermatology community.

For more information or to register as a participating site [CLICK HERE](#).



CONTINUED PROFESSIONAL DEVELOPMENT WITH THE AUSTRALASIAN DERMATOLOGY REGISTRY

As we strive to enhance our practice and provide the best care for our patients, continued professional development (CPD) remains a cornerstone of our professional journey. The Australasian College of Dermatologists (ACD) continues to lead the way by integrating innovative approaches to ensure that practitioners remain at the forefront of their field. One such opportunity is the chance to claim CPD points through involvement with the Australasian Dermatology Registry (ADR). Here's how you can benefit from this initiative and enhance your professional growth.

What Can I Claim?

The ACD acknowledges the significance of registry participation in professional development. Active involvement in the ADR qualifies for Category 1, 2 and 3 CPD points, aligning with ACD's commitment to fostering continuous learning and improvement.

Category 1: Educational Activities

Attending ADR-hosted information sessions and events.

Category 2: Reviewing Performance

Engaging in detailed discussion at ADR-hosted information sessions and events.

Engaging in a detailed discussion on implementing the ADR within your clinic.

Category 3: Measuring Outcomes

Participating in the ADR and attending ADR-hosted information sessions and events.

Reviewing entered data, benchmarking, and analysing registry data or evaluating one's own data quality, documentation completeness and patient outcomes.

How Do I Claim CPD?

- **Engage with ADR:** Attend ADR information sessions and engage in discussions to claim Category 1 and 2.
- **Become a Participating Site:** Become a participating site, and access patient, clinic and aggregate registry reporting via the ADR Clinician Portal to claim Category 3.
- **Document Your Involvement:** Keep a detailed record of your involvement with the ADR.
- **Submit Your CPD Claim:** Visit the ACD's CPD portal and complete the CPD claim form.

We encourage all members to embrace this opportunity. Engaging with the ADR not only enriches your own practice but also contributes to a collective effort that enhances dermatological care across Australasia. By aligning your professional development with real-world data and collaborative research, you ensure that your skills and knowledge remain cutting-edge.

Update on the ADR: Reporting and ACD Category 3 CPD

In April 2024, the ADR hosted an online information session designed to guide dermatologists on implementing and participating in the ADR and explain how these activities align with CPD requirements.

If you are a dermatologist or dermatology nurse interested in accessing a recording of this information session, please email registry@australasiandermatologyregistry.org.au.



ACKNOWLEDGEMENTS

Our Sites

We extend our heartfelt gratitude to the numerous sites that are participating in and contributing data to the Australasian Dermatology Registry. Your dedication and commitment are integral to the success of this national initiative. (<https://australasiadermatologyregistry.org.au/governance/participating-sites/>).

We also wish to pay a special thanks to the clinicians, researchers, and administrative staff at our sites, who have worked diligently to ensure the accuracy and completeness of the data. Your professionalism and enthusiasm are deeply appreciated.

Our Sponsors

Without the support of our sponsors the registry would not be possible. (<https://australasiadermatologyregistry.org.au/governance/sponsors-and-partners/>).

Foundation Sponsors



Funding Providers



The Australasian Dermatology Registry is a national collaboration between dermatologists, facilitated and coordinated by the Skin Health Institute.



To find out more about the registry

Please contact Julie and Chelsea at:

Email | registry@australasiadermatologyregistry.org.au

Phone | +61 3 9623 9470

Website | <https://australasiadermatologyregistry.org.au/>

