

ADDN

NEWSLETTER

ISSUE 7 – NOVEMBER 2022

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IMPORTANT DOCUMENTS:

A revised ADDN Publication and Data Access Policy (version 2) will be circulated to all ADDN stakeholders in the coming weeks. The current ADDN Data Dictionary (version 4.5) is linked below, with version 4.6 to be circulated in early 2023.

[ADDN Data Dictionary version 4.5](#)

CONTACT DETAILS:



Phase 3 of ADDN is being administered by the University of New South Wales (UNSW). Correspondence to the project team can be sent to the following email addresses:

Enquiries: ADDNinfo@unsw.edu.au

Ethics/Governance: ADDNethics@unsw.edu.au

Welcome ADDN partners and friends to the 7th edition of the ADDN newsletter.

It seems that another year has gone by in a flash. Since our last newsletter in June 2021, and despite the continued impact of COVID-19, ADDN has continued to grow, with 10 additional centres joining ADDN. We hope that the rollout of the vaccination program has brought some stability back to your centres and your interactions with people with diabetes.

The past year marked the dawn of a new phase for ADDN, with the commencement of ADDN Phase 3, in late 2021. You can read more about this exciting new period in this newsletter, including progress made towards the expansion of CGM evaluation in pregnancy, and about our recent publications including collaborations between ADDN and other international diabetes registries.

We look forward to your continued participation and hope you join us in our journey to achieve the goals proposed over the next three years.

We hope you enjoy reading our newsletter!

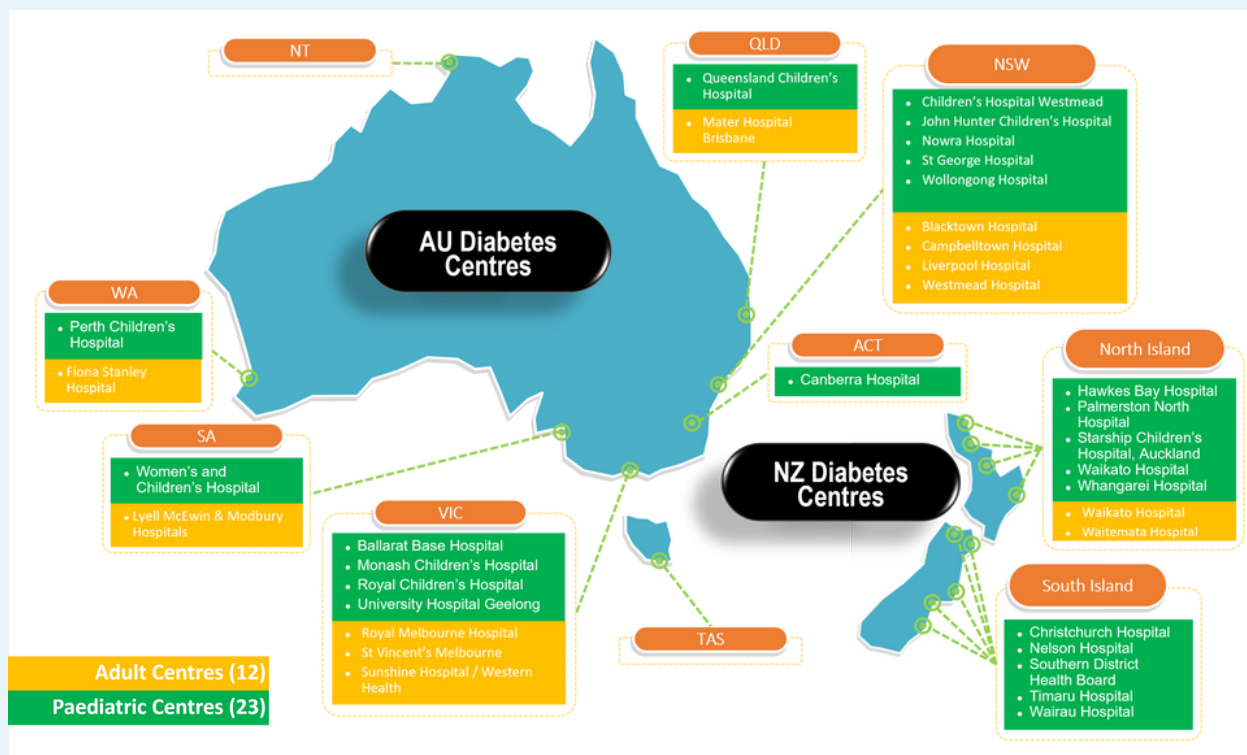
Professor Maria Craig
ADDN Medical Director





PARTICIPATING CENTRES

35 diabetes centres contributed data to ADDN in August 2022



This map shows the Australasian diabetes centres currently participating in ADDN, including:

23 sites in Australia (13 paediatric, 10 adult)

12 sites in New Zealand (10 paediatric, 2 adult)

LATEST DATA LOAD: SEPTEMBER 2022

Benchmarking and completeness reports from September 2022 have now been provided to sites, and CGM reports are on their way. A snapshot is available at www.addn.org.au/latest-load.

To everyone involved in submitting data to ADDN this year:

Thank You!

The ADDN Registry holds both clinical and demographic data on **26,461** people with diabetes across the lifespan, including **22,472** people with type 1 diabetes who attended at least 1 visit. ADDN has now collected data from over **337,549** clinic visits dating back to 1987.

PROCESS FOR RESEARCH ENQUIRIES

We encourage ADDN Study Group members and others to submit a research proposal involving ADDN data. This can be done on our website, by scanning the QR code below, or by using the following linked [Research and Data Enquiry Form](#). Proposals will be asked to provide:

1. A completed [Data Extract Request Form](#) (prior to the review of available data)
2. Evidence of [local institutional ethics approval](#) (prior to the provision of data)
3. [Data Agreement Form](#) signed by all researchers (prior to the provision of data)
4. Sufficient acknowledgement of ADDN: (prior to the publication of any articles, abstracts, posters or presentations)
 - a. [ADDN Study Group](#) members as authors
 - b. [JDRF](#) as the funding body





WHAT'S NEXT FOR ADDN

Announcements, priorities for Phase 3, and future events

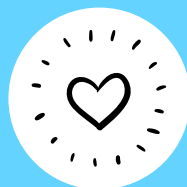
OUR HIGHLIGHTS FOR 2022 AND BEYOND



Congratulations to all the recent publications, abstracts, posters and presentations which have used ADDN data for research (Page 4)



The Royal Women's Hospital (Victoria) is the first ADDN site to start collecting data as part of the CGM in pregnancy sub-study













A big welcome to the 10 new diabetes centres who have joined ADDN since June 2021 (listed below)



The ADDN project team are planning a face-to-face stakeholder meeting for early 2023. Keep an eye out for more info!



- | | |
|---|--|
|  Canberra Hospital, ACT |  Timaru Hospital, NZ |
|  Ballarat Base Hospital, VIC |  Waikato Hospital, NZ (Paediatrics) |
|  Hawke's Bay Hospital, NZ |  Wairau Hospital, NZ |
|  Nelson Hospital, NZ |  Waitemata Hospital, NZ (Adults) |
|  Palmerston North Hospital, NZ |  Whangarei Hospital, NZ |

With continued funding from JDRF until September 2025, we have now entered into Phase 3 of ADDN, where we will continue to expand on our previous programs and activities. Our core priorities are to:

- (1). Achieve representative coverage and benchmarking in young people across Australasia,
- (2). Maximise data quality and completeness,
- (3). Utilise data linkage to enhance ADDN's capabilities, and
- (4). Extend engagement with stakeholders including policymakers, researchers, industry & the diabetes community.

As part of a new governance model, we have recently welcomed additional dedicated, full-time staff to the ADDN project team, and are in the process of forming a more agile steering committee.

Benchmarking and completeness reports will continue to be the highlight of participation in ADDN.

We are now officially registered as a [clinical quality registry](#) and will continue to provide feedback on how centres are treating and managing people with diabetes, and hope to expand to multiple new centres in 2023.

TIMELINE FOR THE NEXT DATA LOAD

Load starts



15 Feb 2023

Cut-off for cleaning



15 Mar 2023

Final dataset



16 Mar 2023

Benchmarking reports



30 Mar 2023

PLEASE INCLUDE VISIT DATES PRIOR TO & INCLUDING 30TH DECEMBER 2022

RECENT PUBLICATIONS

Includes collaborations with international registries



- Impact of the COVID-19 pandemic on long-term trends in the prevalence of diabetic ketoacidosis at diagnosis of paediatric type 1 diabetes: an international multicentre study based on data from 13 national diabetes registries. **Birkebaek NH, et al.** *Lancet Diabetes & Endocrinol.* Nov 2022 [10.1016/S2213-8587(22)00246-7]
- Diabetic Ketoacidosis at Onset of Type 1 Diabetes and Long-term HbA1c in 7,961 Children and Young Adults in the Australasian Diabetes Data Network. **Clapin H, et al.** *Diabetes Care.* Dec 2022 [In Press]
- Decreased occurrence of ketoacidosis and preservation of beta cell function in relatives screened and monitored for type 1 diabetes in Australia and New Zealand. **Wentworth JM, et al.** *Pediatr Diabetes.* Sep 2022 [10.1111/pedi.13422]
- Differences in retinopathy prevalence and associated risk factors across 11 countries in three continents: A cross-sectional study of 156,090 children and adolescents with type 1 diabetes. **Bratina N, et al.** *Pediatr Diabetes.* Sep 2022 [10.1111/pedi.13416]
- Suboptimal Glycaemic Control in Adolescents and Young Adults with Type 1 Diabetes from 2011 to 2020 across Australia and New Zealand: Data from the Australasian Diabetes Data Network Registry. **James S, et al.** *Pediatr Diabetes.* May 2022 [10.1111/pedi.13364]
- A collaborative comparison of international pediatric diabetes registries. **Lanzinger S, et al.** *Pediatr Diabetes.* May 2022 [10.1111/pedi.13362]
- Universal Subsidized Continuous Glucose Monitoring Funding for Young People With Type 1 Diabetes: Uptake and Outcomes Over 2 Years, a Population-Based Study. **Johnson SR, et al.** *Diabetes Care.* Feb 2022 [10.2337/dc21-1666]
- Longitudinal audit of assessment and pharmaceutical intervention for cardiovascular risk in the Australasian Diabetes Data Network. **Robertson CA, et al.** *Diabetes Obes Metab.* Feb 2022 [10.1111/dom.14584]
- Benchmarking care outcomes for young adults with type 1 diabetes in Australia after transition to adult care. **Rueter P, et al.** *Endocrinol Diabetes Metab.* Oct 2021 [10.1002/edm2.295]
- Glycaemic outcomes in Australasian children and adults with Type 1 Diabetes: failure to meet targets across the age spectrum. **Holmes-Walker DJ, et al.** *Intern Med J.* Jun 2021 [10.1111/imj.15426]

If your clinic is interested in becoming an ADDN centre, please contact our program team at **ADDNinfo@unsw.edu.au** for further information.

You can also call us on **(+612) 9348 1326**, or submit a general enquiry on our website at

www.ADDN.org.au/contact-us

Data Tip!

From the ADDN Management Team

For this quarter we would like to share the updated ISPAD clinical consensus guidelines for diabetic ketoacidosis (DKA). The biochemical criteria for diagnosis of DKA have recently changed:

Hyperglycemia (BGL **>11 mmol/L**),
Venous pH **<7.3** / serum bicarbonate **<18 mmol/L**,
Ketonemia (blood β -hydroxybutyrate **≥ 3 mmol/L**) / moderate or large ketonuria

Source: **Glaser et al., 2022**

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