ADDN Steering Committee

ADDN2 Progress Update

30 November 2018

AUSTRALASIAN DIABETES DATA NETWORK

Prepared by:
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Milestones 2017 / 2018

	Milestone Schedule			
No	**Milestone**	**Progress**	**Due Date**	**Milestone Payment**
1-9	2016 Milestones	✓ All completed	Completed	$964,500
10-14	2017 Milestones	✓ All completed	Completed	$460,500
16	Annual Report Year 2	✓	15-Jan-18	$18,000
15	11,500 patients in database 9 Paed, 4 Adult sites	✓	30-Mar-18	$75,000
19	14,000 patients in database 9 Paed (Phase1 & Phase2), 5 Adult sites	✓ JDRF Approved	15-Sep-18	$75,000
17	15 Applications Received and 90% Applications Granted	✓ JDRF Approved	01-Nov-18	$75,000
18	Sustainability and Leverage	✓ JDRF Approved	15-Nov-18	$75,000
20	Annual Report Year 3/4	In progress	15-Jan-19	$18,000
21	Publications	✓ Submitted 15/11/18, JDRF Approved Pro-rated	15-Feb-19	$75,000

ADDN Sites

Paediatric sites

1. John Hunter Children's Hospital, NSW
2. The Children's Hospital at Westmead, NSW
3. St George Hospital, NSW
4. Lady Cilento Hospital, QLD
5. The Women's and Children's Hospital, SA
6. Monash Children's Hospital, VIC
7. The Royal Children's Hospital, VIC
8. Perth Children's Hospital, WA
9. Starship Children's Hospital, Auckland, New Zealand

Adult sites

1. Westmead Hospital, NSW
2. Mater Hospital Brisbane, QLD
3. Lyell McEwin & Modbury Hospitals, SA
4. The Royal Melbourne Hospital, VIC
5. St Vincent's Hospital, VIC
6. Western Health (Sunshine Hospital), VIC
7. Fiona Stanley Hospital, WA

Sites Update

Paediatric sites in progress

- Canberra Hospital, ACT (2018)- ethics approved, DPMS installation still in discussion with ACT Health, data expected Aug 2019
- Christchurch Hospital, NZ – ethics approved, DPMS installed, data expected Feb 2019, no payments
- Dunedin Hospital, NZ – ethics approved for SDHB, data expected Feb 2019, no payments
- Royal Hobart Hospital, TAS (2018) – Tasmania Health did not approve DPMS as state-wide diabetes clinical system, discussions continuing
- Flinders Medical Centre, SA - DPMS installed, not an ADDN site this phase

Adult sites in progress:

- Westmead Hospital, NSW (ethics & governance approved, diabetes module development in the Cerner system underway, full data expected Feb 2019)
- Blacktown Mt Druitt Hospital, NSW (diabetes module development in the Cerner system underway, data expected Feb 2019)
- Ipswich Hospital, QLD (ethics approved, using BioGrid, in discussions)
- Bankstown-Lidcombe Hospital (SWSLHD), NSW (using BioGrid, in discussions)

NDSS CGM Evaluation Update

Report

- Final CGM Evaluation Interim Report submitted to Government and officially accepted on 9 October 2018.
- Full Year Report due in March 2019. A statistician engaged by JDRF is performing preliminary analysis of the current CGM data.

MOU/agreements

- A Data Request form was submitted to the Data Release Advisory Panel on 2 October as required by Government
- Pending approval, MOUs will be signed between JDRF and DA/NDSS to link NDSS data, and between DA/NDSS with BioGrid for the transfer of NDSS data. JDRF will sign a service agreement with BioGrid governing data linkage.

QoL

- The CGM Working Group continues working on a QoL questionnaire and protocol (this is currently unfunded).

NDSS CGM Evaluation Report

Full Year Report, March 2019

NOTE:

- The Full Year Report due in March 2019 will include **ALL** related CGM data collected by ADDN. Please focus efforts to collect these data items so that they are as complete as possible.

Data Dictionary v4.1	Data Item Name
1.37	CGM Start Date
4.47	CGM Type
4.48	Continuous Glucose Monitoring Usage (CGM %)
4.49	CGM Make
4.50	CGM Model
4.51	Severe Hypoglycaemia Episodes
4.52	Moderate Hypoglycaemia Episodes
4.53	Diabetic Ketoacidosis (DKA) Episodes

ADDN Sustainability

Assessment of the potential future directions for the Australasian Diabetes Data Network (ADDN)

JDRF commissioned Dr Rachel Swift (Swift Outcomes) to write a report after consultation with selected JDRF personnel, ADDN PIs, APEG, ADS, BioGrid, project staff and two international T1D registry experts

- This report was circulated and discussed at the last Steering Committee meeting in September.
- One key recommendation is to hold an all-day ADDN Strategy Meeting early in 2019. JDRF will be coordinating and funding this event, likely in March 2019. Further updates will be provided in the coming months.
- Funding update – JDRF has reviewed the acquittals from organisations and a reconciliation of the budget completed

ADDN Registry

ADDN Data Cleaning

LIVE

https://www.addn.org.au/login

REMINDER:

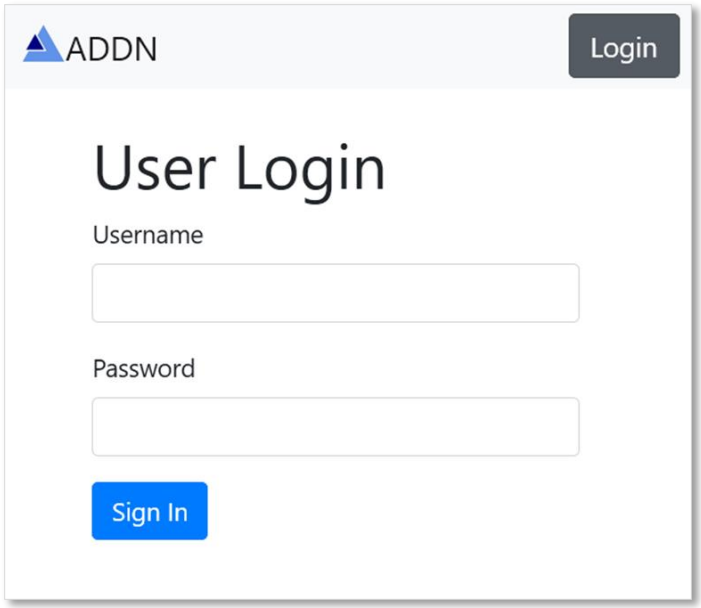
- The ADDN Data Cleaning website is accessible for sites to continue verifying data 24/7
- Verified information will be stored and saved until the next load and not overwritten

ADDN Registry

ADDN Data Repository

- The Final Dataset now in the ADDN Repository is from data created from the August 2018 load
- Benchmarking reports for September 2018 can be downloaded from the ADDN Repository site:

https://www.addn.org.au/login



Data Loads

Data load schedule for 2019

Next load → Feb 2019

	Feb 2019	Aug 2019
Data load due date	15 February	1 August
Cut off date for data cleaning	15 March	30 August
Final Dataset created for reporting	18 March	2 September
Benchmarking Report available	29 March	13 September
Data to include visit dates up to (inclusive)	31 December 2018	30 June 2019

NOTE: Next data upload is February 2019

The next Final Dataset will be created from this load.

Data for the CGM full year report will also use this Final Dataset.

ADDN Data Dictionary

New version 4.1

A new version of the ADDN Data Dictionary v4.1 has been released. This was approved by the Steering Committee at the meeting on 21 September 2018.

Summary of key changes:

1. Changed Gender value from Undetermined to Indeterminate
2. Changed range for BMI
3. Insulin Regimen - Added new values 'Do-It-Yourself' (DIY) and 'Hybrid Closed Loop' (HCL)
4. Pump Make and Model combined into single Insulin Pump with predefined values
5. Removed CGM Used
6. Renamed Continuous Glucose Monitoring to CGM Type
7. Renamed and redefined HospHONK to Hyperosmolar Hyperglycaemic State (HHS)
8. Corrected the measurement for AER
9. New fields added to Patient:
   pH and Bicarbonate
10. New fields added to Visit:
    NPDR, PDR, Maculopathy, Cataract, Cataract Extraction, Focal Laser, Panretinal Photocoagulation, Vitreal Injection, eGFR (calculated)
11. Guidelines on how to enter test results updated in Guide for Use

ADDN Data

Repository Dashboard

ADDN Participants - Centre Summary as at 03-Sep-2018

			Patients With ≥1 Visit by Disease Type and Year						
Centre	**Type**	**Total Patients**	**All**	**Type 1**	**Type 2**	**Other**	**2017**	**2018**	**Date of Export**
NSW-NTL-JHC	Paediatric	441	441	441	0	0	294	258	01-Aug-2018
NSW-SYD-CHW	Paediatric	2,394	1,500	1,386	42	72	870	690	01-Aug-2018
NSW-SYD-SGP	Paediatric	65	65	64	1	0	44	40	01-Aug-2018
NSW-SYD-WMH	Adult	43	38	38	0	0	17	37	31-Aug-2018
NZ-AKL-SCH	Paediatric	961	961	843	73	45	524	467	31-Aug-2018
QLD-BNE-LCH	Paediatric	1,224	821	799	5	17	461	405	31-Aug-2018
QLD-BNE-MAT	Adult	625	625	625	0	0	436	506	31-Aug-2018
SA-ADL-LMM	Adult	701	701	701	0	0	485	455	08-Aug-2018
SA-ADL-WCH	Paediatric	966	953	903	34	16	710	584	23-Aug-2018
VIC-MEL-MCH	Paediatric	1,390	1,383	1,298	42	43	544	72	30-Aug-2018
VIC-MEL-RCH	Paediatric	2,025	2,024	1,925	44	55	1,280	1,139	01-Aug-2018
VIC-MEL-RMH	Adult	1,632	1,632	1,632	0	0	637	559	30-Aug-2018
VIC-MEL-SVH	Adult	532	532	532	0	0	257	74	01-Aug-2018
VIC-MEL-WEH	Adult	175	175	175	0	0	144	64	01-Aug-2018
WA-PER-FSH	Adult	529	527	526	0	1	314	207	13-Aug-2018
WA-PER-PMH	Paediatric	1,616	1,599	1,465	94	40	1,109	1,055	28-Aug-2018
All Centres		*15,319*	*13,977*	*13,353*	*335*	*289*	*8,126*	*6,612*	-

N = 13,977 patients
Paediatrics (n) = 9,747
Adults (n) = 4,230

Visits up to 30 Jun 2018
Total visits = 199,764

Final Dataset created
3 Sep 2018

Last data loaded
31 Aug 2018

AUSTRALASIAN DIABETES DATA NETWORK

ADDN Data

Data load payments

- Data load and patient payments meeting the ADDN data quality standards will be based on the Final Dataset
- Payments for the last data loads (February & August 2018) are on hold pending budget discussions

Reminder to raise outstanding invoices for statements issued in 2017 if you have not done so

Payment Criteria

ADDN centres will be paid for each patient loaded to ADDN and meeting the payment criteria as follows:

- Core Data Set A ≥ 90% complete AND
- At least one visit after 2012 (paediatric centres) OR 1999 (adult centres)

Patients due for payment will be calculated as:

Total number of patients meeting payment criteria – total number of patients previously paid for

Policies / Procedures

Final Versions

- **Data quality policies**

  ADDN Phase 2 Data Quality Assessment Plan v1.3

  Defines the data upload process and schedule (approved 21 July 2017)

  ADDN Phase 2 Data Quality Standards v2.2

  Has requirements for measuring ADDN data quality standards and meeting completeness targets (approved 17 June 2017)

- **Dataset and data dictionary**

  ADDN Data Dictionary v4.1

  Incorporates the revised Core data items (approved September 2018)

- **Publication and data access**

  ADDN Publication and data access policy v1.2

  Conditions for data access, use and publications including EOI collaborations

  SOP Data Research Enquiry v1.0

  Internal steps for data requests and EOI process

Expression Of Interest (EOI)

Recent Expressions of Interests:

Research Enquiries / Proposals

See separate document 'ADDN Research Proposals' for an up-to-date list and status of research proposals

New requests for data received in Nov 2018:

- Steven James - Adolescents and Young Adults with Type 1 Diabetes in Australia and New Zealand: A Health and Service Use Scoping Study
- Jane Holmes-Walker - Benchmarking health care outcomes for Young Adults with diabetes in Western Sydney

Research Enquiries / Proposals

The ADDN Research Enquiry Form is now available on-line. Click on the following link to commence an initial research enquiry to use the ADDN data:

ADDN Research Enquiry Form

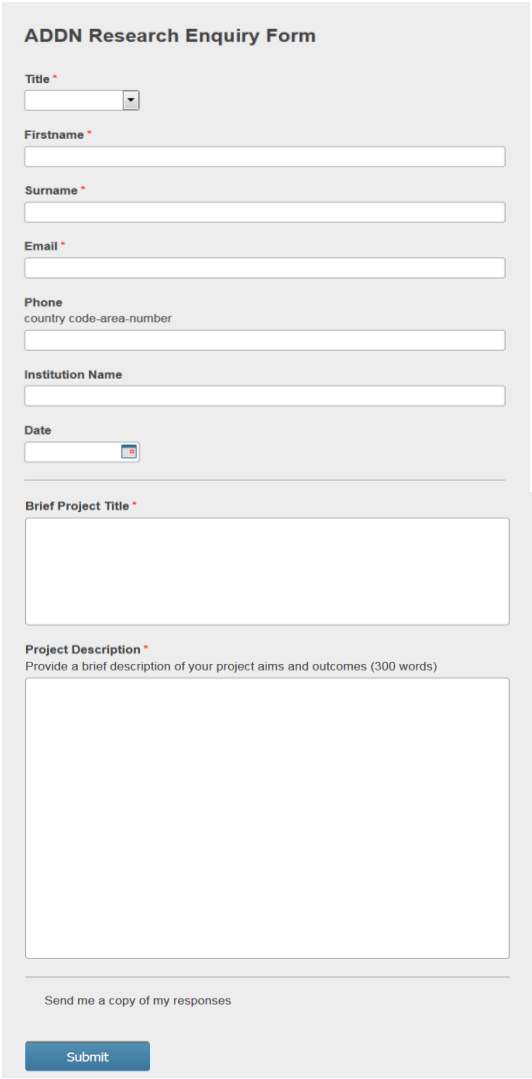
or

visit the ADDN website at:

http://www.addn.org.au/contact-us/

If you have any problems with this form, email us at:

info@addn.org.au



Publications

Published

- *Australasian Diabetes Data Network: building a collaborative resource.* Journal of Diabetes Science and Technology 2016, Vol. 10(5) 1015–1026
- *The Australasian Diabetes Data Network (ADDN): First national audit data on youth with type 1 diabetes*. MJA 206 (3) 20 February 2017
- *Prevalence of Celiac Disease in 52,721 Youth with Type 1 Diabetes: international comparison across three continents.* Diabetes Care 2017;40:1034–1040 (https://doi.org/10.2337/dc16-2508)
  - ↳ Letter in response to comment on the above article by Craig et al. published in Diabetes Care 2017;40:e1–e2 (https://doi.org/10.2337/dci17-0040)

Manuscripts

Accepted/Submitted (#1)

- BMI trajectories paper submitted - H Phelan, NC Foster, A Schwandt, JJ Couper, S Willi, P Kroschwald, TW Jones, M Wu, C Steigleder-Schweiger, ME Craig, DM Maahs and N Prinz on behalf of the Australasian Diabetes Data Network (ADDN) Study Group, the T1D Exchange Clinic Network (T1DX), and the Prospective Diabetes Follow-up Registry (DPV) initiative
- BMI trajectories poster presentation at ADA – M Wu, HT Phelan, A Schwandt, N Foster, JJ Couper, C Steigleder-Schweiger, S Willi, TW Jones, P Kroschwald, D Maahs, ME Craig, N Prinz
- BMI trajectories poster presentation at EASD - A Schwandt, N Foster, H Phelan, C Steigleder-Schweiger, M Wu, JJ Couper, P Kroschwald, SM Willi, TW Jones, N Prinz, D Maahs, ME Craig
- HbA1c trajectories poster presentation at ISPAD – H Phelan, A Schwandt, M Clements, K C Donaghue, C Schroder, N Foster, J J Couper, Ursula Lück, K M Miller, ME Craig, N Prinz, D Maahs
- ADDN benchmarking oral presentation at ISPAD - Helen Phelan, Philip Bergman, Loren Bruns Jr, Fergus Cameron, Melissa Chee, Helen Clapin, Peter Colman, Jennifer Couper, Maria Craig, Elizabeth Davis, Kim Donaghue, P Gerry Fegan, Peter Shane Hamblin, Craig Jefferies, Tim Jones, Bruce King, Jane Makin, Meng Tuck Mok, Richard Sinnott, Jerry Wales, Glenn Ward, Anthony Zimmermann, and the ADDN Study Group
- DKA at onset of paediatric type 1 diabetes oral presentation at ISPAD - V. Cherubini, J. Hermann, K. Åkesson, N.H. Birkebæk, O. Cinek, K. Dovc, R. Gesuita, J.W. Gregory, R. Hanas, S. Hofer, R. Holl, C. Jefferies, G. Joner, B.R. King, E.J. Mayer-Davis, A.S. Pena, B. Rami-Merhar, U. Schierloh, T. Skrivarhaug, Z. Sumnik, J. Svensson, J.T. Warner, N. Bratina, D. Dabelea

Manuscripts

Accepted/Submitted (#2)

- ADDN benchmarking oral presentation at ADC - The Australasian Diabetes Data Network (ADDN): Using a national registry to improve quality in diabetes care - Helen Phelan, Philip Bergman Loren Bruns Jr, Fergus Cameron, Melissa Chee, Helen Clapin, Peter Colman, Jennifer Couper, Maria Craig, Elizabeth Davis, Kim Donaghue, P Gerry Fegan, Peter Shane Hamblin, Craig Jefferies, Tim Jones, Bruce King, Jane Makin, Meng Tuck Mok, Richard Sinnott, Jerry Wales, Glenn Ward, Anthony Zimmermann, and the ADDN Study Group.

Website Analytics

Period 1 Nov – 6 Dec 2018

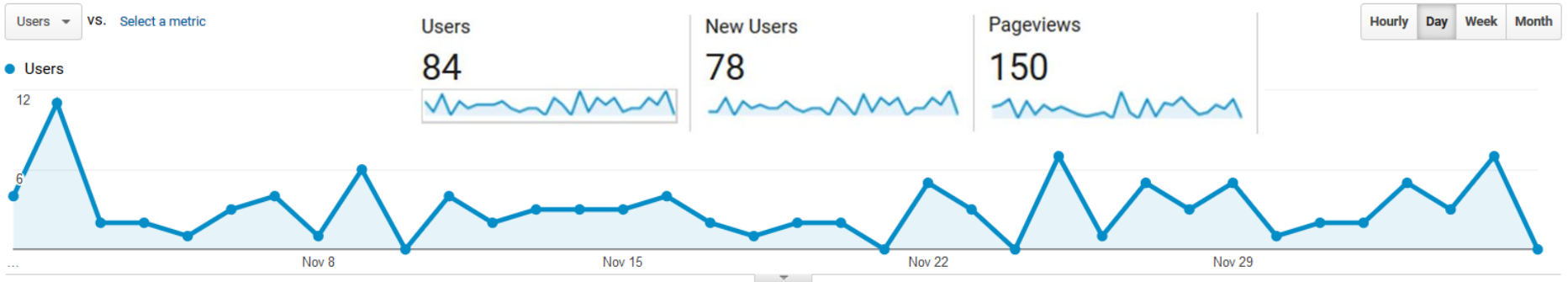
User
An individual person browsing your website (technically, a unique browser cookie).

Pageview
When a page has been viewed by a user on your website.

Unique Pageview
Counted as one page even if viewed multiple times within a single session.

Nov 1, 2018 - Dec 6, 2018

Overview



	Page	Pageviews	Pageviews
		150 % of Total: 100.00% (150)	150 % of Total: 100.00% (150)
1.	/	83	55.33%
2.	/research/	26	17.33%
3.	/governance/	12	8.00%
4.	/who-we-are/	8	5.33%
5.	/news/2017/6/22/prof-peter-colman-awarded-in-the-queens-birthday-honours	5	3.33%
6.	/who-we-are	4	2.67%
7.	/contact-us/	3	2.00%
8.	/news	2	1.33%
9.	/news/	2	1.33%
10.	/research	2	1.33%

	Country	Users	% Users
1.	Australia	53	50.48%
2.	France	10	9.52%
3.	China	6	5.71%
4.	United States	6	5.71%
5.	India	4	3.81%
6.	Brazil	3	2.86%
7.	Bangladesh	2	1.90%
8.	Germany	2	1.90%
9.	Iraq	2	1.90%
10.	Italy	2	1.90%

AUSTRALASIAN DIABETES DATA NETWORK

ADDN Mobile App

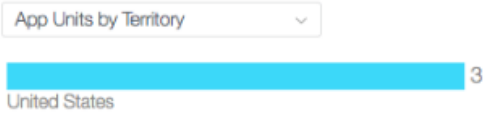
ADDN app

The app went 'live' on 23 June 2017

Developed by eResearch, University of Melbourne, the ADDN Mobile App enables users to compare glycaemic levels (HbA1c) and body weight (BMI) with children from the same age group who have T1D.

Analytics period

6 Sep – 4 Dec 2018



The number of times the app was viewed in the Featured, Categories, Top Charts, and Search sections of the App Store.

1,216
Impressions ▼ 19%

The number of times the app's product page has been viewed on a device.

43
Product Page Views ▼ 26%

The number of first-time app downloads made on the App Store

7
App Units ▼ 46%

AUSTRALASIAN DIABETES DATA NETWORK

Download from Download on the App Store by searching 'ADDN'

Upcoming Meetings / Events

ADDN Steering Committee Meeting Schedule 2019			
NEXT ➡	Friday	12 April 2019	Face-To-Face (Sydney)
	Friday	5 July 2019	Teleconference
	Friday	27 September 2019	Face-To-Face (Melbourne)
	Friday	13 December 2019	Teleconference

Contacts

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