

DIABETES across the LIFECOURSE: Northern Australia Partnership NEWSLETTER

**Welcome to the 2020 September edition
of our Partnership newsletter**

This edition contains articles on two topics: the NT Diabetes in Pregnancy Clinical Register going digital and a snapshot of the Partnership's Indigenous Reference Group.

It also has updates on our research projects including PANDORA, Diabetes In Pregnancy (DIP) Models of Care and from the Youth Diabetes Team. We've also included information about our Annual Education Symposium (23 October 2020) and a list of recent publications.

Thank you all for your support to date. We look forward to strengthening our collaborations in the remainder of 2020 and beyond.

The flyer for the 2020 Virtual Annual Educational Symposium features the following content:

- DIABETES across the LIFECOURSE: Northern Australia partnership** (with logos for HOT NORTH and menzies)
- MY STORY. OUR JOURNEY. DIABETES IS EVERYONE'S BUSINESS**
- DIABETES across the LIFECOURSE: Northern Australia Partnership 2020 Virtual Annual Educational Symposium**
- When:** Friday 23 October, 8.30am to 1.00pm (ACST)
- Where:** Menzies School of Health Research Auditorium, JMB Building (Bldg 58), Royal Darwin Hospital Campus & various Live Satellite Sites across Kimberley, Northern Territory and Far North Queensland
- With international keynote speaker Professor Dana Dabalea, University of Colorado, USA
- and Professor Sue Kildea and Associate Professor Yvette Roe from Molly Wardaguga Research Centre, Charles Darwin University, AUS
- Topics discussed will include:**
 - Diabetes in pregnancy
 - First 2000 days and diabetes
 - Type 2 diabetes in young people
 - Lived experiences
- Participants can attend via zoom or at specified satellite sites.
- Registration is free, but essential. **Find out more and register here:** <https://bit.ly/3sMI0pD>.
- The Symposium will be followed by our Annual Clinical Reference Group & Indigenous Reference Group Meeting - 1:00pm to 4:30pm, Darwin.
- For more information please email NTDIPpartnership@menzies.edu.au or visit <http://www.dipp.org.au>

The **2020 Diabetes Across the Lifecourse Annual Educational Symposium** will be held virtually this year. The theme of this year's Educational Symposium is *"My Story. Our Journey. Diabetes is everyone's business"*. There will be a focus on lived experience this year in response to last year's evaluations.

Please save the date to your calendars- **23 October 2020**. Registrations will open soon and are required although this event will be largely virtual.

We encourage you to attend. Last year:

- 82% of respondents strongly agreed that the presentations were relevant to their work.
- 91% strongly agreed that they learnt something new from the symposium.
- 63% strongly agreed that they would make changes to practice and/or policy following the presentations.
- 66% strongly agreed that they would recommend *others* to make changes to practice and/or policy following the presentations.



As in past years, the Partnership's Clinical Reference Group and the Indigenous Reference Group meetings will be held during the week. We will be in touch with further details.

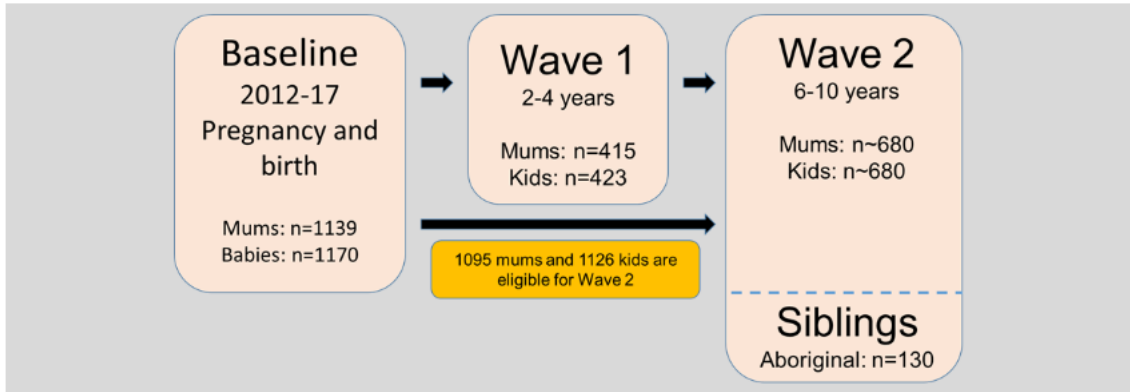
Research Updates

Pregnancy And Neonatal Diabetes Outcomes in Remote Australia- PANDORA Study update
By Dr. Elizabeth Barr PANDORA study lead epidemiologist

PANDORA wave 2 health assessments

Wave 2 is the second follow-up of the PANDORA cohort (see Figure on p.3). The children of the PANDORA cohort are now aged 5-8 years old and are being invited with their mothers to return for a health assessment. The Wave 2 assessments commenced in November 2019, and the teams in Darwin and in Alice Springs have already seen over 70 mothers and their children. Thanks to Alison Simmonds, we are using electronic data collection forms within REDCap to ensure accurate data collection. Research teams are supported by Dr. Emily Papadimos and Dr. Mary Wicks who commenced their PhDs at Menzies School of Health Research (Charles Darwin University) and Ms. Anna Trill (medical student, University of Melbourne).

Figure: PANDORA study phases



COVID-19 restrictions meant that face-to-face assessments were paused from April to July 2020. Face-to-face assessments have now re-commenced with the implementation of strict COVID-19 safety guidelines for participants and research staff. Thanks to Jo Kelaart and team for establishing these procedures.



Key research findings from PANDORA Wave 1 study

Dr. Anna Wood (PhD candidate) investigated rates of conversion from gestational diabetes to pre-diabetes or diabetes. Dr. Wood showed that 22% of Aboriginal women with gestational diabetes in PANDORA developed diabetes, and 11% developed pre-diabetes after 2.5 years. This highlights the importance to support culturally appropriate prevention programs for Aboriginal and Torres Strait Islander women (Wood *et al*, 2020).

Women who had gestational diabetes should have a glucose check in the postpartum period, preferably the OGTT at 6-12 weeks but if not, the HbA1c test at 4 months or later, and then annually to check for type 2 diabetes.



Dr. Danielle Longmore (PhD candidate) investigated breastfeeding rates among women with and without diabetes in pregnancy. Dr. Longmore reported that Aboriginal women had high rates of breastfeeding, but women with type 2 diabetes had difficulty starting breastfeeding. Thus, continuation and support for in-hospital breastfeeding services are needed, in particular for Aboriginal and Torres Strait Islander women with type 2 diabetes.



Thanks to all participants for volunteering their time and supporting the study!

Youth Type 2 Diabetes Team Update

The Youth Diabetes Management Program aims to develop, pilot and evaluate culturally appropriate diabetes management programs for Aboriginal and Torres Strait Islander children and youth with type 2 diabetes across Northern Australia (Northern Territory, Kimberley and Far North Queensland). The end of 2019 saw the completion of data collection and analysis for the formative work in the Top End (NT) – *Understanding Their Stories* – the experiences of Aboriginal children and young people with type 2 diabetes. Data collection in FNQ and the Kimberley is ongoing.

This year, we are in the process of sharing these findings back to participants, community and health services. In addition, we have commenced of the *Co-design of youth-friendly, culturally appropriate models of care with Aboriginal and Torres Strait Islander Children and Youth with type 2 diabetes*. This body of work has been funded by the Commonwealth Government until the end of 2022 for Northern Australia. The key project outputs will be:

- 1. Enhanced model of care for broader implementation.**
- 2. Production of age-appropriate and culturally-appropriate educational resources**
- 3. Description of prevalence rates of type 2 diabetes in Aboriginal and Torres Strait Islander youth.**

In Central Australia work is being undertaken to adapt a culturally-safe behavioural intervention program to reduce diabetes risk in 6-10 year old's. Specifically, we are working with Central Australian Aboriginal Congress and other NT health and education services, communities and families to inform the adaptation of a First Nations American youth diabetes prevention program to the local context and ensure it aligns with local needs, priorities and cultures. This project will be complete by the end of 2020.

Staff comings & goings:

In 2020 we said goodbye to two of our long-standing staff members Paula Van Dokkum (far left) who has been the Northern Territory Diabetes in Pregnancy Partnership Program Central Australia Coordinator since 2013 & Marie Kirkwood (second) who has been at Menzies for 11 years and the PANDORA Top End Project Coordinator for 8 ½ years.

We welcome back casual nurse research assistant Smitty Dornan who will be assisting with PANDORA Wave 2 visits. Anthony Gunther is the new Project manager for the Youth Diabetes Team (with Dr Renae Kirkham) and their team includes Emma Weaver- Alice Springs (fourth), Shiree Mack- Alice Springs (fifth) and trainee Jade Morris (not pictured).



NT & FNQ Diabetes in Pregnancy Clinical Register & Models of Care update: Focus on NTDIP Clinical Register - the next generation

The Partnership has recently been awarded a grant through the Medical Research Future Fund (MRFF). The project will enhance the existing Diabetes in Pregnancy Clinical Registers in the Northern Territory and Far North Queensland and co-design initiatives that promote breastfeeding and healthy weight before, during and after a pregnancy with diabetes. This project is funded from June 2020- May 2025 and will be developed with Aboriginal and Torres Strait Islander women, families and community members.

In Far North Queensland the Clinical Register referral process continues. The new MRFF grant will enable the FNQ team to explore ways to transition the clinical register to a more sustainable system and focus on enhancing Models of Care via the co-design initiatives.

In the NT, the grant will be used to take the DIP Clinical Register to the next stage, the digital age. This exciting development promises greater coverage, accuracy and timely delivery of Clinical Register reports using hospital and primary care information systems.

As many of you know, the previous manual, paper-based process was labour intensive but one of the benefits was being able to talk to the women face- to- face. Over the next few months the team will be busy working with stakeholders to gain and formalise all the necessary approvals to ensure that women and clinicians are informed of these changes and can support the women’s decision to opt out. We are consulting with each ACCHO in the NT and inviting participation in this service.

We are currently distributing the findings of 2019 data via the Annual Clinical Register reports (also on the website). The data collected by the Clinical Register from 2011- 2019 is for clinicians to use also and we encourage you to contact us if you wish to explore additional questions about women with DIP for example, weight gain in pregnancy.

In the NT, we have many people past and present to thank as we prepare for the next generation of register data, it has been many years in the making. In particular we would like to acknowledge the hard work and support on the ground of Francesca Timms – Diabetes support nurse at RDH and Pet Dymock, the ward clerk of 6A; the managers & staff of Antenatal, birth centre & 6A; Elizabeth Watkins, Cherie Whitbread, Helen Lamech & all the diabetes educators at RDH and Sumaria Corpus at Danila Dilba; our clinical champions in Katherine and Gove. Thank you to our sole Clinical Register operator in Alice Springs Paula Van Dokkum. We remain grateful to the data experts Robyn Liddle (Menzies), Leanne O’Neil (DoH) and Anna Beecham (and the Acacia Team) for all their advice and unwavering belief that ‘it can be done’.

The success of the project has always relied on your feedback, please continue to keep in touch with your questions, concerns and discussion via twitter feed or email: ntdippartnership@menzies.edu.au



We’re now on twitter! Follow us @diabpartnership



To opt out of the register you can contact the RDH Diabetes Team on 8922 8888 (switch to be put through to pager 0628); fax Top End: 08 89226740 or email: DIPClinicalRegister.TH5@nt.gov.au. For resources go to the Partnership’s website: <https://dipp.org.au/>

Partnership's Indigenous Reference Group snapshot

The Partnership's Indigenous Reference Group is currently looking for new members from community-controlled agencies and organisations. Invitations have been extended to Directors to nominate a representative to be part of discussions and decisions that shape the Partnership's future. If you wish to be involved or would like to know more, please contact Sian or Vanya on ntdippartnership@menzies.edu.au.

The Indigenous Reference Group's (IRG) main priority is to fill an advisory role between the participants, communities, researchers, students and investigators undertaking NT-based research for the Partnership's projects. The IRG aims to provide strategic advice concerning all aspects of the Partnership and provide Indigenous knowledge on the best ways to ensure the research is conducted in a culturally appropriate way.

IRGs are important for incorporating Indigenous knowledge into research. By incorporating an IRG in to a permanent component of the Partnership, it is more likely that research will be conducted in a culturally sensitive and culturally appropriate way. It is critical our research is respectful of local communities and conducted appropriately and respectfully with Aboriginal and Torres Strait Islander people.

The IRG aims for 2020 are:

1. To increase stakeholder membership within the IRG to ensure a broader representation of stakeholders across the Northern Territory.
2. To ensure appropriate contributions with research co-design, research grant and funding applications.
3. To ensure that culturally appropriate community consultation and engagement occurs, and that knowledge translation and dissemination of research findings are given back to communities.
4. To ensure contributions, mentorship and translation of Indigenous knowledge is appropriate when working with research students and investigators.

The IRG supports Menzies in fulfilling their Reconciliation Action Plan, Strategic Plan 2021 and Employment Strategy by promoting Indigenous researcher involvement, Indigenous employment, skills improvement and knowledge enhancement.



Partnership publications: Dec 2019- August 2020

Gilbert E, Collins R, Webster V, Boyd N, Maple-Brown L, Boyle J, Smith-Vaughan H, **Using co-design to develop a culturally responsive reproductive health learning resources for Aboriginal and Torres Strait Islander youth**, [published online ahead of print, 2020 Jul 29]. *Health Promot J Austr.* 2020;10.1002/hpja.392. doi:10.1002/hpja.392

MacKay D, Kirkham R, Freeman N, Murtha K, Van Dokkum P, Boyle J, Campbell S, Barzi F, Connors C, O'Dea K, Oats J, Zimmet P, Wenitong M, Sinha A, Hanley A.J., Moore E, Peiris D, McLean A, Davis B, Whitbread C, McIntyre H.D., Mein J, McDermott R, Corpus S, Canuto K, Shaw J.E., Brown A, Maple-Brown L and on behalf of the Diabetes Across the Lifecourse: Northern Australia Partnership, **Improving systems of care during and after a pregnancy complicated by hyperglycemia: A protocol for a complex health systems intervention.** *BMC Health Serv Res.* 2020;20(1):814. Published 2020 Sep 1. doi:10.1186/s12913-020-05680-x

Longmore DK, Barr ELM, Wilson AN, Barzi F, Kirkwood M, Simmonds A, Lee IL, Hawthorne E, Van Dokkum P, Connors C, Boyle JA, Zimmet P, O'Dea J, McIntyre HD, Brown ADH, Shaw JE, Maple-Brown LJ, **Association of hyperglycemia in pregnancy, including type 2 diabetes with breastfeeding at discharge, and to 6 months in the PANDORA study,** *Diabetologia* (In press).

Hare MJL, Barzi F, Boyle JA, Guthridge S, Dyck RF, Barr ELM, Singh G, Falhammar H, Webster V, Shaw JE, Maple-Brown LJ, **Diabetes during pregnancy and birthweight trends among Aboriginal and non-Aboriginal people in the Northern Territory of Australia over 30 years,** *The Lancet Regional Health Western Pacific*, 2020.100005, doi.org/10.1016/j.lanwpc.2020.100005

Maple-Brown LJ, Graham S, McKee J, Wicklow B, **Walking the path together: incorporating Indigenous knowledge in diabetes research,** *The Lancet Diabetes & Endocrinology*, 2020; 8(7), 559-560. doi:10.1016/S2213-8587(20)30188-1

Maple-Brown LJ, Hampton D, **Indigenous cultures with similar colonization history share the challenge of intergenerational diabetes,** *Lancet Global Health* (Invited commentary) [Volume 8, Issue 5](#), May 2020, Pages e619-e620. [doi:10.1016/S2214-109X\(20\)30072-3](https://doi.org/10.1016/S2214-109X(20)30072-3)

Longmore D, Barr ELM, Barzi F, Lee I-L, Kirkwood M, Connors C, Boyle J, O'Dea K, Zimmet P, Oats J, Catalano P, McIntyre HD, Brown ADH, Shaw JE, Maple-Brown LJ, on behalf of the PANDORA study research team, **Social and economic factors, maternal behaviours in pregnancy and neonatal adiposity in the PANDORA cohort,** *Diabetes Research & Clinical Practice*, 2020;161:108028. Doi:10.1016/j.diabres.2020.108028.

Wood A, Mackay D, Fitzsimmons D, Derkenne R, Kirkham R, Boyle J, Connors C, Whitbread C, Welsh A, Brown A, Shaw J, Maple-Brown L, **Primary health care for Aboriginal women in remote communities after a pregnancy with hyperglycemia,** *International Journal of Environmental Research and Public Health*, 2020 Jan 22;17(3). pii: E720. doi: 10.3390/ijerph17030720.

Lee I, Barr ELM, Longmore D, Barzi F, Brown A, Connors C, Boyle J, Hampton V, Lynch M, Lu ZX, O'Dea K, Oats J, McIntyre HD, Zimmet P, Shaw JE, Maple-Brown L, **Cord blood metabolic markers are strong mediators of the effect of maternal adiposity on fetal growth in pregnancies across the glucose tolerance spectrum: the PANDORA study,** *Diabetologia*, 2020 Jan 8. doi: 10.1007/s00125-019-05079-2. [Epub ahead of print]



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