

YOUTH OUTREACH FOR DIABETES (YOuR-Diabetes) 2008 - 2016

Implementation and evaluation of a Systems Navigation Model of Transition and Care for Non-Metropolitan Young Adults with Type 1 Diabetes

YOuR-Diabetes is a program of work carried out as a partnership between the University of Newcastle, Hunter New England Local Health District and Diabetes NSW. Funding was provided by NSW Health (Institute of Rural Clinical Services and Teaching) in 2007 and 2009, by JDRF in 2013 and by a NHMRC Partnership Grant (2011 – 2016).

Summary of Outcomes

Phase 1 (2008-2010): Pilot investigation work

- Compared service usage and diabetes outcomes at Royal Prince Alfred Hospital, Sydney, Young People's Clinic in Newcastle and rural areas of HNELHD¹
- Interviewed young adults in rural areas of HNELHD about engagement with available diabetes services²
- Pilot care coordination model, including a telehealth proposal (based in Narrabri)

Phase 2 (2010-2011): Scoping insulin pump therapy for young people with Type 1 diabetes

- Cross-sectional questionnaire for young people to project insulin pump service support demand once they reach adult services³
- Interviews with staff around resource requirements and challenges of providing insulin pump therapy⁴
- Interviews with young people around costs of insulin pump therapy
- Resources developed include:
 - Hunter New England Local Health District Clinical Guideline 2011: Generic Guidance for Commencement of Continuous Subcutaneous Insulin Infusion (CSII).
 - Hunter New England Local Health District Clinical Guideline 2011: Use of patient controlled insulin pumps in hospital.
 - Insulin Pump Therapy: A Simple Guide to the management of people with type 1 diabetes using an insulin pump (flip chart)

Phase 3 (2011-2016): Developing a care co-ordination model

- Preparation for transition pathway (available through JHCH and CHIME), supporting fact sheets
- Development of YOuR-Diabetes Database and training materials to enable proactive co-ordination of care and service review for young adults transitioning to adult services (to age 30 years); now available to HNE staff
- Organised and/or contributed to diabetes professional meetings in regional/ rural areas

- Annual audits of service usage and outcomes (2011-2014); prediction of development of vascular complications⁵
- Training materials developed and a telehealth service set up for young people not otherwise accessing Specialists⁶
- Several trials of a care coordination model, none of which were successful for a variety of reasons
- Data sets still being analysed:
 - Final audit of service usage and outcomes (2012-2014)
 - Service usage of young adults for the first two years after final paediatric appointment
 - Service usage and outcomes for young people living in HNE continuously for five years up until 2015
 - Interviews with young adults about the process of transition and their experiences with adult services
 - Interviews with diabetes services staff about the process of transition

- ¹ Perry L, Steinbeck KS, Dunbabin J, Lowe J. Lost in Transition? Access, uptake and outcomes of services for young people with Type 1 diabetes in regional New South Wales. *Medical Journal of Australia* 2010;193:8:444-9.
- ² Perry L, Lowe J, Steinbeck K, Dunbabin J. Services doing the best they can: Service experiences of young adults with type 1 diabetes mellitus in rural Australia. *Journal of Clinical Nursing* 2012 21:1955-1963.
- ³ Perry L, James, S, Steinbeck K, Dunbabin, Lowe, J. Insulin Pump Use In Young People With Type 1 Diabetes. Accepted *Journal of Evaluation in Clinical Practice* Oct 2016.
- ⁴ James SJ, Perry L, Gallagher R, Dunbabin J, Steinbeck K Lowe J. Supporting patients with type 1 diabetes using continuous subcutaneous insulin infusion therapy: disconnections and disarray. Accepted *Journal of Evaluation in Clinical Practice* Oct 2016
- ⁵ James S, Perry L, Gallagher R, Lowe J, Dunbabin J, McElduff P, Acharya S, Steinbeck K. Service usage and vascular complications in young adults with type 1 diabetes. *BMC Endocrine Disorders* 2014 14:39.
- ⁶ Dunbabin J, Perry L, Steinbeck K, Haas M, James S, Lowe J. Can Telehealth engage young people with type 1 diabetes: Experiences from the YOuR-Diabetes Project. *Australian Diabetes Educator* 2015 18(3):32-34.