Charles Darwin University
Northern Territory Government
Department of Health and Community Services
GRADUATE SCHOOL FOR HEALTH PRACTICE

1+1= A Healthy Start to Life - Research Report

The *1+1 = A Healthy Start to Life Project: Targeting the year before and the year after birth in Aboriginal children in remote areas* is a three stage baseline, intervention and post-intervention study designed to improve maternal and infant health for remote dwelling Aboriginal families in Maningrida and Wadeye. We are investigating how services can be better designed to increase community involvement in improve early detection of problems and increase the effectiveness of multidisciplinary practice during pregnancy and the year after birth. This study is funded by the National Health and Medical Research Council, the NT Research and Innovation Board and the Helen and Bori Liberman Family. An Australian Research Council funded project in partnership with the Department of Health and Community Services and Danila Dilba Aboriginal Medical Service is looking at Indigenous families and birth which is also feeding into this work.

Where we are up to ….

On the 7th October 2008 we held a one day Advisory Committee meeting at Charles Darwin University (CDU). Twenty-nine people attended, 13 from NT Health Government, three from other Australian universities and 13 from CDU and Menzies. During this meeting, we worked with colleagues on an early redesign of the patient journey for women and babies from our two communities.

On the next day, we hosted a 'Costing Maternity Care' workshop. We invited 5 researchers, specialising in health care costing from other Australian universities and two government health economists to help us to establish a credible, feasible costing model that could be used for innovative models of care in the NT and nationally.

A short workshop was held on the 9th October to continue discussions around the development of indicators for the 1+1 = A Healthy Start Project. Malinda has identified a large number of existing indicators from gray and scientific literature including those related to international and national maternal infant health, Indigenous health and reproductive health.

A project officer (Anne Davis) has been appointed by the Department of Health and Families. We will be working with Anne to develop the Remote Link Team to provide continuity of care for the women who come to the town for pregnancy and birth. We will evaluate the new service and the care received by women, from the research sites from an Aboriginal Health Worker and midwife in town. We anticipate that women will be better supported for their time in Darwin.

We are delighted to have this opportunity to report it to you. Please contact myself or any of the researchers mentioned here if you want more information or have any queries about the content of this Newsletter.

Lesley Barclay AO PhD
Professor; Health Services Development and Chief Investigator

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Advisory Committee Workshop – what happened?

Lesley Barclay overviewed the study including the initial CRC funded workshop with key stakeholder and Maningrida and Wadeye women in 2006. This led to successful NHMRC and ARC funding and we now have a number of PhD students all working under the umbrella of the 1+1 study.

Terry Dunbar provided an update on her PhD where she is critiquing the impact of policy on birthing practices in the NT. She is working under the guidance of an Indigenous Reference Group and a co-researcher from one site. She has completed a number of interviews and focus groups. There is also a vignette board where women are invited to record stories around dates set out on a snake. An example of one story as a case study describes a

woman who had 3 children, the eldest, 35 years ago on her country, the next was in an urban tertiary hospital 30 years ago and the last one was in a regional hospital.

Suzanne Belton: is a medical anthropologist Suzanne's focus is on women's understandings and meaning of pregnancy, birth and mothering which is imbedded in the socio-cultural context. She provided an overview of the narratives of 7 women and their families from one community. The analysis shows that;

- The 'check up' at the community clinic was accepted and valued by the women
- They were very familiar with community clinic staff, knew them by name and trusted them.
- Women disliked being in Darwin by themselves, were confused and lonely.
- Most women were illiterate and did not participate in their care plan nor understand the hospital system.
- Women were often threatened and lived with insecurity while in Darwin.
- Women were unable to identify their caregivers in the hospital and did not know them. Women did not routinely see an Aboriginal Liaison Officer.
- Some women had multiple journeys to town and back- for both medical complications and family reasons. The latter were costly and unplanned.

Sarah Ireland: Suzanne Belton presented Sarah's work as she was on leave. Sarah has reviewed the medical histories of 32 women who gave birth in the community. She also collected 7 of these women's narratives of their pregnancy and birth experience. This data was presented in the May 08 advisory group meeting and updated at this meeting with further data from records.

Malinda Steenkamp: Malinda presented the process and progress of establishing indicators for the 1+1 Study. This included the development of a framework for the indicators based on a cube model. It also involved reviewing the literature and identifying existing indicators around Maternal and Reproductive Health, Child Health, Indigenous Health, etc. She collated all identified indicators resulting in a list of more than 200 indicators being considered for use in the 1+1 Study. Malinda will use a Delphi process (i.e., a structured and systematic way to establish consensus among a group of experts) to establish a core set of process and outcome indicators for monitoring health service performance for the 1+1 study. She aims to establish indicators that could be useful for health service providers and policy makers when assessing health performance at the community level. The proposed indicators will be linked conceptually to the patient journey. Malinda also reported that she received her first dataset the week before the Advisory Committee meeting and will start analysis on it now.

Lorna Murakami-Gold: Lorna's focus is on assisting nurses, as one of the frontline workers in the NT, to engage more effectively with Aboriginal and Torres Strait Islander women and their families. To do this she is developing an educational support program that assists nurses examine their own cultural beliefs as well as their biomedical professional and institutional culture. Exploration will include how cultural, professional and institutional beliefs and attitudes impact on engagement with Aboriginal and Torres Strait Islander families.

This educational support program, called Dealing with Difference, has been developed to complement and to be delivered along side the Family Partnership Model which is a problem solving model that incorporates active listening and communication strategies for health professionals to work in partnership with families in client centred goal setting.

The Dealing with Difference content and process will be carefully evaluated from an educational perspective. Health professionals will be supported by fortnightly clinical supervision sessions for up to six months.

Sarah Bar-Zeev: (presented by Sue Kildea) Sarah has collected a significant amount of baseline data as part of her situational analysis for the 1+1 study. Data collected includes:

- 750 matched mother – infant pairs across two communities.
- 120 hours of observational data in hospital and Remote Health Centres.
- 61 in depth interviews with key stakeholders including: remote health staff, Royal Darwin Hospital maternity and paediatric staff, specialist outreach staff, hostel managers, Aboriginal Liaison Officers, Patient Assisted Travel Scheme (PATS) staff and Maternal and child health managers.

Sue presented a summary of the data analysis of the qualitative interview and observational data as follows:

- Currently the service focuses on acute pregnancy management.
- Social issues such as violence, family support, access to food/money etc are not addressed.
- There is good continuity of carer in both communities with the midwives well accepted by the women.
- There seems to be an excessive administration burden on the midwives, particularly in one community.
- There is insufficient access to consistent obstetric advice in both communities.
- Inadequate time for maternity services, particularly in one community
- Communication across the services is a particular problem

Joanne Curry: introduced patient journey modelling and how it could be used to inform the study and assist stakeholders improve services. Patient Journey Modelling is the graphical technique that describes the woman's journey. It identifies the overall process involved with the movement of the woman through the system of care. The patient journey model can analyse how this journey can be improved via the removal of unproductive excessive activities, process duplication, care variability and improved communications between the patient, their cares and clinicians.

The Advisory Committee and researchers identified a number of issues through group discussion in the afternoon that could significantly improve care:

- Fragmented Care

The fragmentation of care when women arrive in town was a major problem and created risk of medical error and social and emotional distress. (This should be greatly improved in the Remote Links Team)

- Organisation of health centre services and workforce

The method used to organise time, workload and staff skills varied considerably between Community A and B. In Community A, clinical staff were less available for clinical activity overall and 30% of the midwives/nurses time was occupied with administrative tasks. Their midwifery and child health time was restricted to particular times due to other Health Centre priorities. Little time or no spent outside the health centre in either community. Consistent models of care in specialised fields such as MCH, mental health and chronic diseases based on clinic size and staffing a population are worth exploring.

- Travel and escorts

The application of the PATS system is problematic with a 'lot of waste in the system'. It was acknowledged that the current PATS guidelines do not support escorts for pregnant women unless they are very young or cannot speak English. However the guidelines are inconsistently applied and this relied on the persistence, effort and support of the individual clinician to attempt to get Defence Materiel Organisation authorisation. There was a lot of discussion around PATS inconsistencies.

Although there is currently no funding for escorts there was unanimous support that this issue needed to be addressed as women and their families report the importance of this.

- Records and communication

Incomplete or incorrect postnatal discharge summaries and the breakdown in communication between communities and Royal Darwin Hospital were identified. Antenatal records are also not always available, there are no client held records and there are serious problems with the tests being duplicated and the discharge summaries. These included the problem with a 'default' in the electronic data collection system that defaulted to 'normal vaginal birth' if this field is not filled in –

this results in some women who have had complications or a caesarean section being labelled as a normal birth. It was mentioned that details can be wrong and that addresses need to be tidied up as they are sometimes duplicated, etc. There are issues with timing of discharge summaries arriving at the health centres. The participants stated that they often do not receive discharge summaries or they do not receive them in a timely manner.

- Culturally insensitive care

Another problem identified is that women are feeling culturally insecure during pregnancy and birth. Aboriginal Liaison Officers and Aboriginal Health Workers were not always present in maternity wards and there are not specified Aboriginal Liaison Officers involved in antenatal care delivery or at Royal Darwin Hospital.

- Inconsistency of medical advice and support

There is little consistent support and information for district medical officers or general practitioners in regard to managing complicated pregnancies. There is a need for consistent obstetric and medical advice to specified communities.

'Costing Maternity Care' workshop

The morning presentations included: 'Costing Intervention from the position of the manager' (Professor Caroline Homer, UTS), A health economists perspective of costing maternity care (Dr. Yuejen Zhao, NT Health Government), 'Modelling costs using interventions as a vital variable' (Professor Sally Tracy, UTS), Costing maternity care in economic evaluation: COSMOS trail and PinC (Bree Rankin, La Trobe University) and Public Sector Midwifery Models & Econometrics: Is there room for a meaningful relationship? (Ros Donellan-Fernandez; Adelaide Women's and Children's hospital). The afternoon was spent incorporating the linens from the working into plan for the 1+1 costing.

Indicators workshop

A short workshop was held on 9th October to continue discussions around indicators for the 1+1 A Healthy Start Project. Malinda has identified a large number of existing indicators from gray and scientific literature including those planned for use in the NT by the Department and Health Families. The ten workshop participants were from three different departments within the NT Department of Health and Families, as well as from CDU and the University of Western Sydney. During the workshop, more than 200 existing indicators were reviewed to identify potential key indicators. Work will continue by further rounds of consultation with relevant people to refine and finalise the list of indicators.

Investigators on the study are: Professor Lesley Barclay, *Project leader*; Professor Jonathan R Carapetis, *child health, infectious disease prevention*; Assoc. Prof Sue Kildea, *PAR, service intervention, evidence based care*; Dr Sue Kruske, *child health, parenting practices, nurse workforce reform*; Professor Gweneth Norris, *management accounting, costing, economic analysis*; Dr Carolyn McGregor, *patient journey modeling, health informatics*; Dr Joanne Curry, *patient journey modeling analyses*; Assoc. Prof Sally Tracy, *innovative service delivery, cost, evaluation, risk management*; Ms Wardaguga; *Indigenous research methods*, Dr Suzanne Belton, *ethnographic studies*, Dr Jacqui Boyle, *Obstetrics, service design*, Dr Ngiare Brown, *Indigenous child health*, Dr Steve Guthridge, *epidemiology, statistical advice*, Noelene Swanson, *remote health service reform.*

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