

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

This newsletter is exciting as, thanks to Sarah Bar-Zeev, Joanne Curry and great cooperation and assistance from remote staff in our research settings, others from DFH and Aboriginal women themselves, we can show you the patient journey based on wonderful baseline data. Sarah Ireland's work is close to completion and will also inform the patient journey work. Malinda Steenkamp is now very close to having her statistical data extracted and again the staff of the Department have been most helpful in facilitating this. We have also been very involved through Terry Dunbar in researching the implementation of the Cultural Safety framework of the Department; this will be an important part of her ARC study. Lorna Murakami-Gold is progressing well with the design of a study to test the effectiveness of a training package titled 'Dealing with Difference'. This will be tested in our research sites to see if it improves interaction between health service providers and the women attending those services.

An important part of this project is the cost implications so we are having a 'Costing Maternity Care' workshop in October. We have invited researchers from other Australian states who are also introducing new models of care, economists and experts in costing to come up with better ways of costing maternity care. We look forward to sharing with you the results of this early next year.

We also look forward to working with colleagues through our Advisory Group in October following feedback informed by our baseline data. We aim to work with them to redesign the patient journey for women and babies from our two communities. The participatory action research side of the study, combined with opportunities resulting from the intervention, has meant that we have already contributed to other exciting innovations for care led by the DFH for remote women coming to town before birth. A project officer is about to be appointed and will be working on the 'remote links team', designed to ensure women from the research sites receive continuity of care and support from an Aboriginal Health Worker and midwife; and are better supported for their Darwin hostel time or hospital based care.

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

An analysis of maternal health services for remote dwelling Aboriginal women and infants from the Top End of Australia

- **Sarah Bar-Zeev.**

Field work for Sarah Bar-Zeev's maternal health service analysis has now been largely completed in Maningrida, Wadeye and at RDH. One arm of the study has been to develop a model of the current patient journey undertaken by mothers from the two remote communities through the NT health system during the antenatal, intra-partum and postnatal episodes. A further model of the patient journey undertaken by infants from Maningrida and Wadeye during the 1st year of life has also been developed.

The patient journey model in this study is presented from the service provider perspective. It identifies the processes involved with the movement of a patient through the healthcare system and analyses how the quality and safety of services can be improved through the elimination of discontinuities in care provision, duplicated or excessive service activities and processes and improved communication between patients and service providers.

We have found that women and infants experience discontinuities and multiple service handovers in the patient journey at every point where the patient care is transferred from the patient's primary home community to RDH for health care and when the patient returns home again. These points are places that add risk and breakdown in the service is likely to occur. The findings of this study in relation to the patient journey will be presented in detail at the October Advisory Group meeting in Darwin and will be distributed to all stakeholders in a report in 2009. Detailed statistical analysis of 750 women and infant records will have to wait until next year as Sarah herself will have a baby in a few weeks.

A very different journey Sarah Ireland with Concepta Narjic

- **Sarah Ireland**

Sarah Ireland, an honours student with the Graduate School of Health Practice continues with her research. Her study explores the experiences and beliefs of Aboriginal women who birth in remote communities with minimal help from the current model of care.

Sarah has recently completed an audit of some of the women's medical records. It covers the years from 2003-2007, and the inclusion criteria include those women who:

- Present for the first time in their last trimester of pregnancy for antenatal care
- Receive less than 5 antenatal care appointments
- Receive no antenatal care during pregnancy
- Give birth in Wadeye

She is analysing a number of variables such as: the number of pregnancies and live births; stage of pregnancy at first presentation; place of birth; time and stage of labour at presentation to the Health Centre; number of antenatal visits; relevant medical history such as cardiac, renal conditions or diabetes and the neonatal outcome: weight and APGAR score. This information is being complemented by narratives collected by co-researcher Ms Concepta Narjic. Sarah's thesis is due at the end of this year.

Pathways and experiences: an exploratory ethnography

- **Suzanne Belton with Concepta Narjic**

Seven women are sharing their experiences and opinions of their journey into 'town' for 'sit down business'. The journeys have all been eventful and different. One husband travelled into town to be with his wife and the other women were accompanied by female relatives. Six babies have been born and we expect the seventh in the next few days. We have more baby boys than girls and they are now at home with their families. A large

number of deaths in the community impacted on the data collection process but Suzanne has a trip planned in September to collect the complete birth stories with Concepta. The Aboriginal Translation Service has assisted with making an audio tape about the aims of the research and consent process in Murin Patha. Ms Isobelle Walker has also assisted with collecting one particularly difficult birth story which involved a long admission. We look forward to presenting these personal journeys later this year.

- **Sue Kruske with Thomasina Hayes-Bohme**

To date seven women have been recruited from Maningrida with two people already having their babies. We have identified an Indigenous researcher in Maningrida, Thomasina Hayes-Bohme who is herself a young mother with an 11 month old infant. Thomasina will support the project through collecting the stories of the young pregnant women and working closely with visiting researchers. It is hoped that she will continue with the project and contribute to the intervention phase and further data collection.

Another research assistant has been appointed to assist in the collection of data when the women come to town. Isabelle Walker is a non-Aboriginal woman who worked as a receptionist at the Maningrida health centre for over 10 years and is well known to community members and visiting health staff. Isabelle is available to visit the women when they come into Darwin and continues to collect data about their journey.

How have Government health policies and practices impacted on Aboriginal birthing at Galiwin'ku, Larrakia and Cobourg since the 1930s

- **Terry Dunbar**

A substantial amount of the primary data has been collected from Galiwin'ku. A further two visits will be undertaken during October this year to clarify stories and back translation material. Initial negotiations with one of the Larrakia families indicated support to commence soon with a range of data collection activities.

During the past several months many hours have been devoted to data collection, analysis and writing of the Aboriginal Medical Services Alliance of the Northern Territory's (AMSANT) Report entitled "*Cultural Security: What is the 'right way' for culturally safe and effective provision of health and community services? Aboriginal people comment on their experiences and suggest a better way to work together*". In support of the partnership between the Department of Health and Families and AMSANT for Change Management processes within the health, family and children's services across the Northern Territory it was important to present the preliminary findings from the AMSANT Report during the first stage of negotiations with departmental staff. These presentations and workshops occurred during August and September 2008. It is anticipated that this work will provide important insights from the field data and literature to form the basis of a chapter for the thesis.

The first interview with a medical staff member who worked in the Northern Territory in the late 70s to 90s provided some valuable leads to follow up for the case studies with health professionals. In addition a current Senior Staff member of the Department has also agreed to be interviewed and will advise of other potential participants for the study. The juggling act continues with my attempts to secure a time and place with contacts for the Cobourg region.

Engaging families: critiquing the notion of partnership for Indigenous families

- **Lorna Murakami-Gold**

The focus Lorna's component of the project is to deliver, evaluate and refine over time an education intervention entitled 'Dealing with Difference' (DwD) training package. This package has been specifically developed for health professionals (midwives and child health nurses) delivering health and parenting services to Indigenous families. The DwD content examines the notion of culture; ethnocentrism, stereotyping and prejudice. It also explores professional and institutional culture as part of system that can itself validate racism, structural violence and oppression. The purpose of the DwD training package is to assist health professionals to

engage with Indigenous clients and their families more effectively in a partnership. The rationale for undertaking this study originated from Northern Territory Department of Health and Families reports and from anecdotal evidence from Indigenous families who are reluctant to access services, as they perceive the care they receive is different from other clients and tests and treatments undertaken have not been fully explained or understood (Aboriginal Health and Families A Five Year Framework for Action).

The ‘Dealing with Difference’ training package is intended to be delivered following successful completion of the Family Partnership Training (FPT) and has therefore been developed to complement the FPT format. The Family Partnerships Training enables experienced health professionals to fine tune their skills of engaging hard to reach clients to develop trusting, helpful relationships. The FPT has been delivered to over 100 health professionals employed within NT Department of Health and Families.

The DwD training package is under negotiation to be delivered in our two remote sites and the hospital women attend for birth. Ethics application will be submitted shortly to meet the 24th October Human Research Ethics Committee of NT Department of Health and community Services and Menzies School of Health Research deadline.

Establishing population baseline data

- **Malinda Steenkamp**

Malinda Steenkamp has made progress towards data access. She is now close to having unit level record data extracted and again the staff of the Department have been most helpful in facilitating this. Malinda has also been working on establishing relevant indicators for the Healthy Start Project. The aim is to establish a core list of the most valuable and responsive indicators for measuring and evaluating safe and effective health service delivery for remote-dwelling Aboriginal women and children in the Top End of the NT. The proposed indicators will measure a range of issues that are linked conceptually and practically as they describe and report the ‘patient journey’ from pregnancy to the first birthday of the infant. Malinda and Sarah Bar-Zeev, with help from the project team, identified lists of indicators relevant to Aboriginal health, maternal and reproductive health, and the health of infants and children from scientific and grey literature. Malinda developed a framework for the indicators in consultation with the Healthy Start research team (Table 1). She then prepared an initial list containing indicators that was circulated for comment among the research team. Additional sets of indicators were identified and indicators were added to the detailed list. Malinda has now developed a master list of indicators. This list is in the process of being pared down to a list of core indicators considered to be specifically relevant. Another list of additional indicators that might be meaningful for the HSP is also being prepared. These lists will be circulated to the research team and Advisory Group members and will be presented for discussion at the AG Meeting.

Table 1: Framework for 1+1 A Healthy Start to Life Project Indicators

Prenatal/Antenatal	Intrapartum and postpartum	First year of infant’s life
• Health status and health outcomes	• Health status and health outcomes	• Health status and health outcomes
• Determinants of health	• Determinants of health	• Determinants of health
• Health service performance	• Health service performance	• Health service performance

Participatory Action Research

- **Sue Kildea**

As you can probably guess from this newsletter we have a lot happening in this project with co-ordination and communication across the sites, the researchers and the stakeholders a wonderful challenge. This is where the

study starts to get really exciting and the participatory action research nature of the project has meant that findings from the field have been acted on sooner rather than later. We have seen this in the care of women where researchers are not just documenting their stories but are advocating on their behalf in many ways. This has involved encouraging a very young pregnant mum to stay in town when she was about to get a lift with relatives back to her community at 40 weeks of pregnancy (she birthed her baby 24 hours later) and safer care of several women who had serious complications of pregnancy that were being missed by a breakdown in communication in the system.

Returning to the original aims of the study which include targeting Communication, Coordination, Collaboration and Continuity we are pleased to say that we believe the 'interventions/ redesign of the journey' will see significant changes in these areas. Working closely with the DHF, particularly Dr Barbara Paterson and Deirdre Ballinger, on submissions for a 'Remote Links Team' and seeing it about to be established, is tremendous. The 'redesign of the patient journey' will allow us to work with the project officer and key stakeholders to assist this project. Together with the Health Gains Department of the DHF we will be extending the evaluation of the 1+1 project to include the evaluation of this new model of care.

Additionally we have had requests from community women about what should be occurring on the ground and this will be incorporated into the feedback sessions that we are planning in the communities.

The next Advisory Group meeting will be on the 7th of October at 8.30am at Naru (23 Ellengowan Drive Brinkin). An agenda for this workshop will be sent to all Advisory Group members by the 12th September.

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*.

For more information please contact:

Prof Lesley Barclay at (08) 8946 6974 on lesley.barclay@cdu.edu.au or

A/Prof Sue Kildea at (08) 8946 7741 on sue.kildea@cdu.edu.au

Dr. Yu Gao, Project Manager, Research Associate at (08) 8946 6837 on yu.gao@cdu.edu.au