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***THE QUALITY OF MATERNAL AND INFANT  
HEALTH SERVICES AND THEIR UTILISATION BY  
REMOTE DWELLING ABORIGINAL FAMILIES IN  
THE TOP END OF AUSTRALIA***

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THIS THESIS IS SUBMITTED IN FULFILMENT OF THE  
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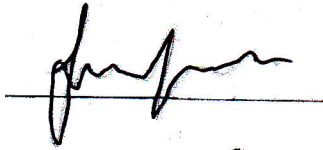
2013

# DECLARATION

## Statement of Authentication

This thesis is submitted to the University of Sydney in fulfilment of the requirement for the Degree of Doctor of Philosophy. The work presented in this thesis is, to the best of my knowledge and belief, original except as acknowledged in the text. I hereby declare that I have not submitted this material, either in full or in part, for a degree at this or any other institution.

Signature:

A handwritten signature in black ink, written over a horizontal line. The signature is cursive and appears to be 'John' followed by a surname that is partially obscured by the line.

Date: 13th August 2013

# STRUCTURE OF THESIS

This thesis is submitted by publication. The thesis commences with a general abstract and a summary of the main findings in each paper. Chapter 1 provides an overview of the background and context of the study. The purpose and objectives of the study are also outlined. Chapter 2 contains a literature review relating to factors associated with the quality and utilisation of maternal and infant health services at a global level and within Australia. Chapter 3 summarises the methodological issues of the study including the design, data collection and analysis procedures. A description of the patient journey undertaken by Aboriginal mothers and infants through the Northern Territory (NT) health system is presented in Chapter 4. This is followed by five peer-reviewed articles that comprise the basis of this thesis in Chapter 5.

To conclude, a discussion relating to the major findings, the limitations and recommendations of the study are given in Chapter 6. All appendices are presented separately in Volume 2 of the thesis. Data collection tools are provided in Appendices 1–11 followed by patient journey models in Appendices 12-13 and a statement of authors' contribution for each publication is presented in Appendix 14.

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# PREFACE

All papers submitted for examination in this thesis have contributing authors.

These authors include:

- (a) Professors Lesley Barclay, Sue Kildea and Sue Kruske
- (b) Investigators on the '*1+1 = A Healthy Start to Life*' project
- (c) Other PhD students

I was responsible for: instigating the research question, obtaining ethics approval, acquiring scholarship, conference and additional field work funding, study design, obtaining access to the data, primary data collection across all study sites, data analysis and interpretation of the results. I was the primary author for the papers in Chapter 5, responsible for the overall writing of these manuscripts and corresponding author on these papers.

I have also co-authored additional papers and reports for the Australian government and health department as a result of this research. My findings have been presented at six national and international conferences during my candidature. Multiple other presentations have been made to the NT Department of Health and various government, policy, health management and clinical staff across Australia. Findings have also been regularly presented to the Advisory Committee of the National Health and Medical Research Council '*1+1 = A Healthy Start to Life*' study and the Local Reference Groups in the remote field sites.

# **ABSTRACT**

## **Aim**

The overall objective of this thesis was to investigate the quality of maternal and infant health services and their utilisation at the primary and referral level, by remote dwelling Aboriginal mothers and their infants. Field studies were conducted in two large remote Aboriginal communities and the major regional hospital located in the Northern Territory of Australia.

## **Methods**

A mixed methods approach was used in this study. Health service use and the quality of service delivery at the primary health care and referral levels were examined in a retrospective cohort study of 412 Aboriginal women during pregnancy, birth and postpartum and their infants (n=413) during the first year of life. In addition, 60 semi-structured interviews were conducted with health service staff and 120 hours of participant observation were undertaken at regional hospital and remote health centres.

## **Results**

The majority of women attended for antenatal care although this often commenced late in pregnancy. High levels of complications and antenatal hospital admissions were identified. Birth occurred at a regional hospital for the majority of women. By six months postpartum, 45% of women had documented postnatal morbidities and 8% required hospital admission. Most women accessed remote health services at least once, however few received PNC.

The quality of antenatal care and the factors that affect the delivery of care were explored. Documentation of routine antenatal screening and investigations was generally of good quality. There was poor health service adherence to local guidelines for follow up of highly prevalent problems including anaemia, smoking and sexually transmitted and urinary tract infections. Inadequate resourcing of remote health

services, discontinuities in care, a lack of service coordination and attitudes and practices of clinicians were the major factors influencing the delivery of antenatal care.

The quality and safety of the discharge process within the health services was also examined. Poor documentation, communication and coordination between hospital and health centre staff and a lack of clinical governance and leadership at the hospital were identified as major factors affecting the standards of care during the discharge process and subsequently.

Health service use during the 1<sup>st</sup> year of life was measured in the infant population. Episodes of the primary health service use and hospital admissions were identified. The analysis showed extremely high rates of health service use and hospitalisation representing an appalling disease burden among this population. Infants presented to the remote health centre about once a fortnight (mean 28 presentations per year, 95% CI 26.4–30.0). Half of the presentations were for new problems, most commonly for respiratory, skin and gastrointestinal symptoms. By one year of age 59% of infants were admitted to hospital at least once, the rate of hospitalisation per infant year was 1.1 (95% CI 0.9–1.2).

Clinicians' adherence to management guidelines for growth faltering and anaemia in Aboriginal infants attending the participating remote health centres were investigated. Sixty-eight per cent of infants were anaemic between six and twelve months of age. Forty-two per cent had documented growth faltering by one year. Analysis of the growth data by the authors however found 86% of infants experienced growth faltering over the first 12 months of their lives. Clinical management and treatment was poor for both conditions. Barriers to health service delivery in these settings were also explored. Fragmented service delivery models, high staff turnover and poor knowledge and skills, absence of Aboriginal workers and leadership and minimal health promotion influenced quality of care.

## **Conclusions**

The results of this study demonstrate that remote dwelling Aboriginal mothers and their infants access health care services frequently, notwithstanding the multiple barriers to care outlined by others. This reflects willingness by families to access



services and highlights an appalling burden of disease in this population that is more aligned with the developing rather than developed world.

Despite the frequent attendance for health care, the existing services failed to provide quality care to many of these mothers and infants evident in the lack of follow up of identified problems during routine antenatal and infant health visits; and also during the hospital discharge process.

The resourcing and organisation of health services and the beliefs, attitudes and practices of clinicians were identified as important factors affecting the quality of care in these settings. A significant change to the organisation of services and delivery of care should be seen as a priority for health care planners. Service redesign based on continuity of care, adequate resourcing of services, work load reform including more efficient use of the Aboriginal Health Worker, child health nurse and midwifery workforce and the integration of community-based health service delivery could play a substantial role in improving maternal and infant outcomes.

**Key words:** *Aboriginal, Australia, remote, maternal, infant, utilisation, quality of care, health services, primary health care, hospital*

# COLLECTION OF PAPERS FOR EXAMINATION

This thesis is presented in the form of five original peer reviewed papers. The research question and the objectives of the study are addressed in one or more of the papers. The order of the papers below represents the order they appear in the thesis.

1. **Bar-Zeev S**, Barclay L, Kruske S, Bar-Zeev N, Yu G, Kildea S. Use of maternal health services by remote dwelling Aboriginal women in northern Australia and their disease burden. *Birth: Issues in Perinatal Care* 2013 (In press).
2. **Bar-Zeev S**, Barclay L, Kruske S, Kildea S. Factors affecting the quality of antenatal care provided to remote dwelling Aboriginal women in northern Australia. *Midwifery* 2013 (In press).
3. **Bar-Zeev S**, Barclay L, Farrington C, Kildea S. From hospital to home: The quality and safety of a postnatal discharge system used by remote dwelling Aboriginal mothers and infants in the top end of Australia. *Midwifery* 2012; 28(3): 366–73.
4. **Bar-Zeev S**, Kruske S, Barclay L, Bar-Zeev N, Carapetis J, Kildea S. Use of health services by remote dwelling Aboriginal infants in tropical northern Australia: a retrospective cohort study. *BMC Pediatrics* 2012; 28: 12– 9.
5. **Bar-Zeev S**, Kruske S, Barclay L, Bar-Zeev N, Kildea S. Adherence to management guidelines for growth faltering and anaemia in remote dwelling Australian Aboriginal infants and barriers to health service delivery. *BMC Health Services Research* 2013; 13: 250.

Following is a summary of the main findings in each paper:

## **PAPER 1:**

**Bar-Zeev S, Barclay L, Kruske S, Bar-Zeev N, Yu G, Kildea S.**

### **Use of Maternal Health Services by Remote Dwelling Aboriginal Women in Northern Australia and Their Disease Burden**

**Major findings:** This is the first study to describe the burden of disease and patterns of maternal health service use by Aboriginal women from two remote communities in northern Australia throughout pregnancy, birth and the postpartum period. High rates of health service use at the primary and referral level were identified throughout these periods, reflecting a willingness by these women to access maternity services and the serious disease burden.

Most women attended antenatal care and visits occurred frequently. High levels of pre-existing co-morbidities and complications were identified during pregnancy. Anaemia, urinary tract infections and preterm birth were among the most common documented complications with prevalence rivalling many developing countries. Avoidable factors were identified that should be addressed with quality care.

Almost one quarter of all women received antenatal hospitalisation. Birth predominantly took place within hospital although more than 10% occurred outside the hospital, typically in the remote health centre. Most women who gave birth outside of the hospital were subsequently transferred for hospital care due to maternal or infant complications. By six months postpartum, 45% of women had documented postnatal morbidities. Most women had accessed the remote health service at least once and 8% of women required hospital admission. Routine postnatal care in the remote health centre was poorly utilised.

## **PAPER 2:**

**Bar-Zeev S, Barclay L, Kruske S, Kildea S.**

### **Factors Affecting the Quality of Antenatal Care Provided to Remote Dwelling Aboriginal Women in Northern Australia**

**Major findings:** This is one of the few studies to examine adherence to antenatal guidelines by clinicians providing antenatal care to remote dwelling Aboriginal women and to describe the factors affecting the delivery of care.

Antenatal care attendance was high and documentation of routine antenatal screening and investigations was generally of good quality. There were however, considerable gaps in the follow up of identified problems for these women despite their regular attendance at health services. Documentation indicated poor adherence to local guidelines for follow up of highly prevalent problems including anaemia, smoking, urine and sexually transmitted infections. Multiple factors were identified to affect the quality of antenatal care including the resourcing and organisation of health services and the beliefs, attitudes and practices of clinicians.

### **PAPER 3:**

Bar-Zeev S, Barclay L, Farrington C, Kildea S.

#### **From Hospital to Home: The Quality and Safety of a Postnatal Discharge System Used by Remote Dwelling Aboriginal Mothers and Infants in the Top End of Australia**

**Major findings:** This is the first study to examine the transfer of maternal and infant care from the hospital to the remote health service following birth in northern Australia. Major discontinuities in care were identified and the inconsistent, *ad hoc* and chaotic nature of communication between clinicians at the hospital and the remote health centres resulted in serious clinical consequences for new mothers and their infants during an already vulnerable period.

Poor discharge documentation, communication and coordination between hospital and remote health centre staff occurred. Additionally, the lack of clinical governance and a specific position holding responsibility for the postnatal discharge planning process in the hospital system were identified as serious risks to the safety of the mother and infant.

## **PAPER 4:**

Bar-Zeev S, Kruske S, Barclay L, Bar-Zeev N, Carapetis J, Kildea S.

### **Use of Health Services by Remote Dwelling Aboriginal Infants in Tropical Northern Australia: A Retrospective Cohort Study**

**Major findings:** This is the first study to describe all episodes and reasons for health care utilisation in the total infant population of the two of the biggest remote communities in northern Australia. Extremely high rates of health service use were identified at the primary and referral level, commencing from birth and continuing throughout the first year. Remote dwelling Aboriginal infants access health care frequently for both routine and acute care, despite the multiple barriers to care outlined by others.

Following birth, one third of infants were admitted to the regional hospital neonatal nursery, predominantly for preterm birth. Once home, most health service use occurred at the local primary health centre, infants presented to the centre about once a fortnight (mean 28 presentations per year, 95% CI 26.4–30.0). Half of the presentations were for new problems, most commonly for respiratory, skin and gastrointestinal symptoms. Remaining presentations were for reviews or routine child health service provision. By one year of age 59% of infants were admitted to hospital at least once, the rate of hospitalisation per infant year was 1.1 (95% CI 0.9–1.2).

## **PAPER 5:**

Bar-Zeev S, Kruske S, Barclay L, Bar-Zeev N, Kildea S.

### **Adherence to Management Guidelines for Growth Faltering and Anaemia in Remote Dwelling Australian Aboriginal Infants and Barriers to Health Service Delivery**

**Major findings:** This is the first study to investigate adherence to management guidelines for growth faltering and anaemia in two remote northern Australian health services and to also describe barriers to health service delivery for Aboriginal infants in these settings.

Sixty-eight per cent of infants had anaemia between six and twelve months of age. Forty-two per cent had documented growth faltering by one year using local guidelines. However, analysis of the growth data by the authors, found that 86% of infants had growth faltering during this period. Clinical management and treatment completion for both conditions was poor. High staff turnover, fragmented models of care and staff insufficiently prepared for their role were barriers perceived to impact upon the quality of service delivery.

# CO-AUTHORED PUBLICATIONS & PRESENTATIONS

## Publications

1. Yu G, Gold L, Josif C, **Bar-Zeev S**, Steenkamp M, Barclay L, Zhao Y, Tracy S, Kildea T. A cost-consequences analysis of a Midwifery Group Practice for Aboriginal mothers and infants in the Top End of the Northern Territory, Australia. *Midwifery* 2012 (In press) .
2. Farrington C, Barclay L, **Bar-Zeev S**, Kildea S, Britten M. How Participatory Action Research supported improvements to the postnatal discharge summary system used for remote dwelling Aboriginal mothers and infants in the Top End of Australia. *Action Research* 2012; 10(4): 387–405.
3. Josif C, Kildea S, Gao Y, Steenkamp M, **Bar-Zeev S**, Kruske S, Barclay, L. *Evaluation of the Midwifery Group Practice Darwin*. Brisbane: Midwifery Research Unit, Mater Medical Research Institute and Australian Catholic University; 2012.
4. Steenkamp M, Johnstone K, **Bar-Zeev S**. Can we count? Enumerating births in two remote Indigenous communities in the Northern Territory of Australia. *Australian and New Zealand Journal of Public Health* 2012; 36(3): 281–4.
5. Steenkamp, M, Rumbold A, Kildea S, Barclay L, **Bar-Zeev, S**, Dunbar T. Measuring what matters for Aboriginal mothers and infants. *Australian Journal of Rural Health* 2012; 20(4): 228–37
6. Steenkamp M, **Bar-Zeev S**, Rumbold, A, Barclay L, Kildea S. Pragmatic indicators for remote Aboriginal maternal and infant health care: Why it matters and where to start. *Australian and New Zealand Journal of Public Health* 2010; 34(1): s5–8.
7. Prime Minister’s Science, Engineering and Innovation Council (PMSEIC). *PMSIEC Working Group on Aboriginal and Torres Strait Islander Health focusing on Maternal, Fetal, and Postnatal Health. The Health of the Adult Begins in the Womb, A Report of the Working Group, 2008*. Canberra; 2008 (co-author).



## Conference Presentations

1. **Bar-Zeev S**, Kildea, S. Utilisation of maternal health services by remote dwelling Aboriginal women from Australia's Top End. Cairns, Australia: Royal Australian and New Zealand College of Obstetrician and Gynaecologists (RANZCOG) Indigenous Women's Health Meeting; 2011.
2. Barclay L, **Bar-Zeev S**, Farrington C, Kildea S, Kruske S. Redesigning maternal and infant health care for remote Australian Aboriginal Communities: Findings from a health services improvement study (symposium). Durban, South Africa: International Confederation of Midwives 29<sup>th</sup> Triennial Congress; 2011.
3. **Bar-Zeev S**, Curry J, Barclay L, Kildea S, Farrington C. (Invited speakers) Patient Journey Modelling Experiences: Remote Aboriginal Maternity Services in the Top End of Australia. Ontario, Canada: Interdisciplinary modelling for improved patient centric care Conference; 2010.
4. **Bar-Zeev S**, Kruske S. What happens during the 1<sup>st</sup> year of life? Health service utilisation by remote dwelling Aboriginal infants. Adelaide, Australia: CRANA (Council of Remote Area Nurses of Australia) National Conference; 2010.
5. Steenkamp M, **Bar-Zeev S**, Johnstone K. Can we count? – A case study of two remote Aboriginal communities. Adelaide, Australia: Public Health Association of Australia 40<sup>th</sup> Annual Conference; 2010.
6. Steenkamp M, Kildea S, **Bar-Zeev S**, Kruske S. Establishing indicators to assess health services for remote-dwelling Aboriginal mothers and infants. Adelaide, Australia: Extending the Boundaries, Casemix Conference; 2008.

## Other Presentations

1. Barclay L, **Bar-Zeev S**. Investing in children in the NT: how is it different? Darwin, Australia: Keynote address: National Investment for the Early Years Association Inaugural Seminar; 2010.
2. **Bar-Zeev S**. What do we know about the use of antenatal care in remote Top end health centres? Darwin, Australia: Remote Outreach Midwives Annual Seminar; 2010.

3. Barclay L, **Bar-Zeev S**. Linking quality of care findings with local protocols and procedures. Alice Springs, Australia: Department of Health and Community Services; 2010.
4. **Bar-Zeev S**. Comparing protocol with practice: Investigating the quality of care delivered to Aboriginal women and infants in remote Australian primary health centres. Darwin, Australia: 1+1 Healthy Start to Life Advisory Group; 2010.
5. **Bar-Zeev S**. Discharge planning and health information systems in the Northern Territory. Darwin, Australia: 1+1 Healthy Start to Life Advisory Group; 2009.
6. **Bar-Zeev S**. Remote Aboriginal infant utilisation of the health care system in their first year of life. Darwin, Australia 1+1 Healthy Start to Life Advisory Group; 2009.
7. **Bar-Zeev S**. How can we best deliver maternity services for remote dwelling women? A qualitative study of health service provider's perceptions of the current health system. Darwin, Australia: 1+1 Healthy Start to Life Advisory Group; 2008.
8. **Bar-Zeev S**. The Patient Journey. Darwin, Australia: 1+1 Healthy Start to Life Advisory Group; 2008.
9. Barclay L, Kildea, S, Kruske S, **Bar-Zeev, S**. Breaking the Cycle. Sydney, Australia: Prime Minister's Science, Engineering and Innovation Council Working Party on Aboriginal and Torres Strait Islander Health; 2007.
10. **Bar-Zeev, S**. Maternal health services for remote Aboriginal women. 1+1 Healthy Start to Life Advisory Group, Darwin, Australia; 2007.

# ACKNOWLEDGMENTS

Eight years ago at a reproductive health conference in Fiji, I had the good fortune of meeting Lesley Barclay. We spoke about our shared interests and work experience in maternal health services in developing countries and in Australia. Lesley described her impressive research plans for a project that would aim to improve health services for Aboriginal women and infants in the Northern Territory. I had previously worked as a remote area nurse and midwife in Aboriginal communities and I was well aware of the challenges and complexities faced by both Aboriginal women accessing the services and by clinicians working in these settings.

Lesley's parting words to me at the end of our meeting were to 'think about doing a PhD with us in Darwin'...and so just over a year later, soon after the birth of our first baby, my husband and I decided to pack up our life in Melbourne and move up north to undertake our PhDs.

I owe enormous thanks and gratitude to Lesley and the rest of my supervisory team, Sue Kildea, Sue Kruske and Joanne Curry for their excellent supervision and guidance throughout my candidature and for introducing me to world of research. In particular, Lesley has continually provided me with unending wisdom and encouragement and also welcomed my family and myself into her home many times, for which I am very appreciative. Yu Gao and Suzanne Belton were also part of the '*1+1 = A Healthy Start to Life*' research team and have provided me with invaluable support and guidance. It has been a privilege to work with a team of dedicated researchers whose endless energy and drive to improving health services and outcomes for Aboriginal women and their infants is always inspiring.

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My family and in-laws have always provided immense support and encouragement over the years, even when it has meant that our work has taken us far from them (and their grandchildren) across Australia and now to Malawi.

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# GLOSSARY

**Air Med** refers to the NT Aerial Medical Service, a government-funded 24-hour emergency medical retrieval service.

**Best Practice Communiqués** are summaries of discussions and subsequent outcomes about a topic that has been addressed by the Best Practice Group. 'The Group reviews current practice and standards and determines appropriate 'Best Practice' to be applied in Northern Territory remote health care' [1].

**CARPA Standard Treatment Manual** is one of the main clinical manuals for primary health care (PHC) providers working in rural and remote Aboriginal communities in the Central and NT. It provides a population approach to PHC and management guidelines and protocols for chronic diseases, emergencies, child health, mental health and drug problems, sexual health and other issues, such as skin conditions, eye and dental conditions, adult health checks and brief interventions.

**Community A and Community B** refers to the two remote community field sites in this study. These names are interchanged with Community 1 and Community 2 in the published papers comprising Chapter 5. These two field sites are not named in accordance with the ethics approval for this study.

**Cultural competence** in health care refers to 'the ability of systems to provide care to patients with diverse values, beliefs and behaviors, including tailoring delivery to meet patients' social, cultural, and linguistic needs' [2, p5].

**Cultural safety** refers to 'an outcome of health practice and education that enables safe service to be defined by those who receive the service' [3, p43]. Strategies aim to create an environment that is 'safe for people: where there is no assault, challenge or denial of their identity, of who they are and what they need' [4, p10], where there is 'shared respect, shared meaning, shared knowledge and experience, of learning, living and working together with dignity and truly listening' [4, p10].

**Cultural security** refers to 'the principle that the construct and provision of services offered by the health system will not compromise the legitimate cultural rights, values and expectations of Aboriginal people. It is a recognition, appreciation and response to

the impact of cultural diversity on the utilisation and provision of effective clinical care, public health and health systems administration' [4, p10]. Cultural security also ensures that 'the delivery of health services is of such a quality that no one person is afforded a less favourable outcome simply because he or she holds a different cultural outlook' [4, p10].

**Country** is a term used by Aboriginal people to refer to their place of Dreaming (see below) and the land to which they belong.

**Dreaming** is a concept that varies in meaning for different Aboriginal groups. 'The Dreaming can be seen as an embodiment of Aboriginal creation which gives meaning to everything. It establishes the rules governing relationships between the people, the land and all things for Aboriginal people' [5].

**Elders** are the key people or custodians of traditional knowledge and lore within a given Aboriginal community or language group.

**Homelands** refer to the traditional land that an Aboriginal person is ancestrally connected to but not necessarily where they live. The term 'Homelands' is often interchanged with 'Outstations'.

**Hostels** refers to the short-term accommodation facilities funded by the Commonwealth Government for use by Aboriginal and Torres Strait Islander people when they need stay in Darwin for reasons such as health care, education, training or family visits.

**Jade Care** is a computer system used at the regional hospital in this study by clinicians to access medical and pathology results.

**Leaders** refer to respected people within the Aboriginal community, such as grandmothers. These people are nominated by other community members themselves and are not necessarily Elders.

**Maternal health** refers to the health of a woman during pregnancy, birth and the postpartum period [6].

**Maternity or maternal health service** refers to all curative and preventive health services provided during pregnancy, birth and the postpartum period at the primary or referral level.

**Outstations** refer to small settlements on Aboriginal traditional lands typically outside of the remote community town centre. Outstations are typically underfunded and under resourced. The term 'Outstations' is often interchanged with 'Homelands'. However 'homelands' is the preferred term of Aboriginal people living on these lands [7].

**PCIS** refers to the Primary Care Information System designed for NT remote health centres. This system was introduced to a number of remote health centres in 2009 and has continued to be rolled out across the NT. It provides an electronic client health record which allows clinicians to document care, prescribe medications, view pathology results and communicate and share client information with clinicians in other health centres. It is designed to replace the paper-based medical record and recall system (see below).

**Recall system** refers to a paper- or computer-based system within the remote health centres to ensure that clients are identified for routine health screening (i.e. pap smears) and disease prevention (i.e. immunisation). It is also used for planned follow-up episodes of care for the ongoing management of chronic diseases or where a review by a clinician is required, such as following an acute illness/injury.

**Regional hospital** refers to a major tertiary hospital in the regional centre of Darwin in the NT. This hospital field site is not named but referred to as the 'regional hospital' in this thesis in accordance with the ethics approval for this study.

**Remote Health ATLAS** is a resource for NT remote health staff that provides governance and information about processes and standards relevant to remote area practice.

**Infant health service** refers to all curative and preventive health services provided from birth at the primary or referral level.

**Shame** refers to 'an Aboriginal cultural concept. It transcends English explanations of 'guilt' or 'disgrace' and relates more to a context where an individual is singled out from the rest of the group for either 'praise or blame' or is forced to behave in a way that



dismisses or rejects larger group obligations. It can also occur when Aboriginal women are made to perform or talk about Women's Business in the presence of males; and vice versa' [8, pxix].

**Skilled Attendant** refers to an 'accredited health professional – such as a midwife, doctor or nurse – who has been educated and trained to proficiency in the skills needed to manage normal (uncomplicated) pregnancies, childbirth and the immediate postnatal period, and in the identification, management and referral of complications in women and newborns' [9]. This term is interchanged with 'skilled maternity care provider' in this thesis.

**Traditional Owners** refers to those people who have ties or connections to specific lands that date back to pre-European contact. These people do not necessarily reside in the same area where these lands are located.

**Top End** refers to the upper half of the NTNT, including Darwin and Katherine.

**Women's business** is an Aboriginal English term that relates to all reproductive and birth matters for Aboriginal women including physical, cultural, ceremonial and religious rites and rituals.

**Women's Business Manual** is the standard treatment manual for women's health care in remote and rural communities in the NT. It provides guidelines and protocols to standardise practice in the areas of obstetrics, gynaecology, well women's screening, menopause, infertility and contraception.

# ABBREVIATIONS

|       |   |
|-------|---|
| ACCH  | Aboriginal Community Controlled Health Services |
| ACMI  | Australian College of Midwives Incorporated     |
| Admin | Administration                                  |
| AHW   | Aboriginal Health Worker                        |
| ALO   | Aboriginal Liaison Officer                      |
| AN    | Antenatal                                       |
| ANC   | Antenatal Care                                  |
| Appt  | Appointment                                     |
| APH   | Antepartum Haemorrhage                          |
| ARM   | Artificial Rupture of Membranes                 |
| BP    | Blood Pressure                                  |
| BMI   | Body Mass Index                                 |
| CARPA | Council of Remote Practitioners Association     |
| CCT   | Controlled Cord Traction                        |
| CDEP  | Community Department Employment Projects        |
| CDU   | Charles Darwin University                       |
| CHN   | Child Health Nurse                              |
| CI    | Confidence Interval                             |

|       |  |
|-------|--|
| COMIC | Continuum of Maternal and Infant Care            |
| CPAP  | Continuous Positive Airway Pressure              |
| CTG   | Cardiotocography                                 |
| CVS   | Chorionic Villus Sampling                        |
| DB    | Database   |
| DoH   | Department of Health                             |
| DHCS  | Department of Health and Community Services      |
| DHF   | Department of Health and Families                |
| DMO   | District Medical Officer                         |
| EDD   | Estimated Date of Delivery or Estimated Due Date |
| ETT   | Endotracheal tube                                |
| FBE   | Full Blood Examination                           |
| FDIU  | Fetal Death In Utero                             |
| FTE   | Full Time Equivalent                             |
| GAA   | Growth Action and Assessment                     |
| GBS   | Group B Streptococcus                            |
| GCT   | Glucose Challenge Test                           |
| GL    | Guidelines                                       |
| GP    | General Practitioner                             |

|         |   |
|---------|---|
| GTT     | Glucose Tolerance Test                  |
| Hb      | Haemoglobin                             |
| HepBSAg | Hepatitis B Surface Antigen             |
| HC      | Health Centre                           |
| HIV     | Human Immunodeficiency Virus            |
| HRN     | Health Record Number                    |
| ICU     | Intensive Care Unit                     |
| IM      | Intramuscular (injection)               |
| IMR     | Infant Mortality Rate                   |
| Info    | Information                             |
| IQR     | Interquartile Range                     |
| IUD     | Intrauterine Device                     |
| IUGR    | Intrauterine Growth Restriction         |
| LBW     | Low Birth Weight                        |
| LUSCS   | Lower Uterine Segment Caesarean Section |
| LV      | Low Vaginal                             |
| MCH     | Maternal and Child Health               |
| MITH    | Midwifery In The Home                   |
| MGR     | Manager                                 |

|           |  |
|-----------|--|
| MGP       | Midwifery Group Practice                     |
| MIH       | Maternal and Infant Health                   |
| MMR       | Maternal Mortality Ration                    |
| MSU       | Mid-stream Urine                             |
| NA or N/A | Not Available                                |
| NHMRC     | National Health and Medical Research Council |
| NNU       | Neonatal Nursery Unit                        |
| NR or N/R | Not Recorded                                 |
| NT        | Northern Territory                           |
| O&G       | Obstetrics and Gynaecology                   |
| Paed      | Paediatric                                   |
| PAR       | Participatory Action Research                |
| PATH      | Pathology                                    |
| PATS      | Patient Assisted Travel Scheme               |
| PCIS      | Primary Care Information System              |
| PET       | Preeclampsia Toxaemia                        |
| PPH       | Postpartum Haemorrhage                       |
| PJM       | Patient Journey Model / Modelling            |
| PHC       | Primary Health Care                          |

|       |  |
|-------|--|
| PN    | Postnatal                              |
| PNC   | Postnatal Care                         |
| PPROM | Preterm Premature Rupture of Membranes |
| Primp | Primipara/primiparous                  |
| PT    | Part-Time                              |
| PW    | Per Week                               |
| RAN   | Remote Area Nurse                      |
| RHC   | Remote Health Centre                   |
| Rh    | Rhesus (factor)                        |
| RDS   | Respiratory Distress Syndrome          |
| ROM   | Rupture Of Membranes                   |
| RN    | Registered Nurse                       |
| SD    | Standard Deviation                     |
| Stats | Statistics                             |
| STI   | Sexually Transmitted Infection         |
| TTN   | Transient Tachypnoea of the Newborn    |
| US    | Ultrasound                             |
| UTI   | Urinary Tract Infection                |
| VBAC  | Vaginal Birth After Caesarean          |

|     |                           |
|-----|---------------------------|
| WBM | Women's Business Manual   |
| WHO | World Health Organization |

# **DEFINITIONS AND TERMINOLOGY**

## **Use of the Terms Aboriginal and Indigenous**

There are two key groups of Indigenous people in Australia; Aboriginal people from the mainland and the island state of Tasmania, and Torres Strait Islanders [10]. Throughout the thesis there are references made to publications that use the terms Aboriginal peoples, Indigenous or Aboriginal and Torres Strait Islander. Where such publications are quoted, the same terminology will be used. I have mostly used the term Indigenous when making international comparisons. The terms non-Aboriginal and non-Indigenous have been cited interchangeably throughout the thesis. These terms refer to all other non-Indigenous Australians. Indigenous and Aboriginal are always capitalised in accordance with the recommendations from 'Communicating Positively, A Guide to Appropriate Aboriginal Terminology' [11].

I have used the term Aboriginal when referring specifically to Australian Aboriginal people from the two participating mainland remote communities in the NT. Aboriginal peoples from specific regions in the country have their own terms of reference by which to describe themselves. In the NT, these terms include Yolngu (Top End) and Anangu (Central Region).

## **Northern Territory Health Department**

During this research the NT Health Department changed its name from the Department of Health and Community Services (DHCS) to the Department of Health and Families (DHF) and is currently the Department of Health (DoH). When referring to this department in the text, I have used the current term DoH.



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# 1 INTRODUCTION

## 1.1 Background and Context

This thesis sets out to analyse and describe the quality and use of maternal and infant health (MIH) services by remote dwelling Aboriginal families in the Top End of Australia's NT.

Australia is a wealthy developed country. There are however, significant disparities in health outcomes for Aboriginal and Torres Strait Islander (hereafter referred to as 'Aboriginal') mothers and infants compared with their non-Indigenous counterparts.

Poor maternal and child health (MCH) foreshadows the early onset of chronic disease [12]. Given these outcomes, it is essential that Aboriginal mothers and infants be provided with high quality health services, particularly preventive primary health care, across the continuum of care and indeed throughout all stages of life to maximise their potential for good health. Little attention has been given to investigate how and when these services are used by Aboriginal mothers and infants and the quality of service delivery.

Most Aboriginal people live in cities and regional areas; one quarter resides in remote communities [13]. Social and economic disadvantage tends to be worse for those living in remote areas, as are health outcomes [14]. These disparities are contributed to by poverty, lower educational attainment, sustained institutional racism, a higher burden of disease that commences early in life and the continuing effects of colonisation [15-16].

Rural and remote dwelling people are further disadvantaged by more limited access to health services and primary health care (PHC) providers than other Australians. This results in reportedly lower health service utilisation than experienced in urban areas and consequently, unmet health needs [17-18].

Provision of MIH health services to remote communities is complex, given vast distances and the small, dispersed populations within the communities themselves.

Often these remote communities lack the infrastructure and human resources to support comprehensive models of health delivery and residents need to access more specialised care and services from regional or urban centres [17]. This can be a traumatic experience for many Aboriginal women who confront unfamiliar surroundings, language and cultural barriers in the hospital and hostel environment when they are transferred from their home community to a regional centre for childbirth. Women also experience increased stress, social isolation and high financial costs as a result of their transfer away from their family and home community for birth [19-22]. As a consequence of this transfer, remote dwelling Aboriginal women frequently discharge themselves from hospital during AN admissions to return to their home community [23-24]. This can result in repeat medical evacuations to hospital, sometimes during labour [25]. Aboriginal children also experience fear and social isolation in the hospital environment and have been known to 'run away' from hospital during their admission [26].

Despite universal services being provided by governments, Aboriginal organisations and dedicated clinicians at both the primary and referral levels, there is much evidence describing the poor performance of the existing health systems in meeting the needs of remote dwelling Aboriginal mothers and children [8, 16, 19-22, 25, 27-31] and the contribution of these systems to ongoing health inequities [32-33].

Many reasons have been identified as contributing to this. These include:

- Health services located in areas that are hard to reach for Aboriginal people and a lack of available and affordable transport options to access services
- The lack of culturally appropriate and responsive health services
- Health services felt to be unwelcoming and unfriendly to Aboriginal people
- Low Medicare (major Australian Government health service program) enrolment among Aboriginal people and financial barriers to accessing private and many community-based services
- Difficulties associated with deployment and retention of adequately skilled and experienced clinicians in remote areas and high turnover

- The decline in access to medical specialists in rural and remote areas and withdrawal of specialist obstetric and surgical services across many communities
- A workforce that is predominantly non-Indigenous and not adequately trained in issues relevant to working effectively with Aboriginal and Torres Strait Islander families and communities
- Poor linkages between private, government and community health sectors
- Limited or often absent continuity of care
- Poor communication between clinicians working in hospitals and the community-based health services and inadequate referral and follow-up systems [32-33].

Poor service coordination or communication among health professionals can result in fragmentation of care [34]. The consequences of fragmented maternity care include adverse outcomes [35-36]. Discontinuities in communication and documentation resulting from multiple handovers across the chain of care providers involved in transitions of care, increases risk of medical errors and compromises patient safety [37]. This risk is greatest at the time of hospital discharge when poor, delayed or absent transfer of information may result in adverse patient outcomes [38-40].

Evidence suggests that providing targeted and culturally responsive health services is a critical step towards improving health outcomes of Aboriginal mothers and their babies. A number of factors have been identified as ‘underpinning’ successful models of MIH care that are known to be effective in improving MIH outcomes [41]. These include providing services that are flexible, community-based, include home visiting and continuity of care and are integrated with other services, such as the hospital. There is also a need to have Aboriginal and non-Indigenous workers providing care in partnership [41].

Nevertheless, understanding the context of health service usage by remote dwelling Aboriginal mothers and infants in the NT and supporting health service improvement is challenged by the significant gap in the knowledge about the quality and use of MIH services at the primary health care and hospital levels. This evidence is crucial for effective policy development, health service planning and program implementation.

### **1.1.1 1+1 = A Healthy Start to Life project**

This research was undertaken as part of a nested baseline study for the five year (2007–2012) National Health and Medical Research Council (NHMRC)-funded study: *'1+1 = A Healthy Start to Life: Targeting the year before and the year after birth in Aboriginal women and infants in remote areas'*.

The *'1+1'* study was a three stage baseline, intervention and post-intervention study with the aim of improving MIH services for remote dwelling Aboriginal families in Top End of Australia's NT. Participatory Action Research (PAR) and a mixed methods design were used with baseline data, evidence and consultation with stakeholders informing interventions for service improvement. Evaluation of the interventions are currently underway and will be compared against the baseline data.

Over the past 30 years there has been a growing body of research, policy statements and reports that have recommended change and improvement in maternal health care services for Aboriginal women and infants from remote communities [20-22, 28, 29, 42-50]. The *1+1* study was developed in response to these recommendations for health service improvement and the long-standing concerns voiced by Aboriginal women about the culturally unsafe practices and quality of maternity services in the Top End [25].

A scoping workshop undertaken in 2006 by researchers from the *1+1* study, together with Aboriginal women from the participating communities, clinicians and policy makers confirmed the significance and feasibility of the study. Aboriginal women reported that the existing maternal health system that separates families around the time of birth and the early postpartum period causes emotional and social distress and results in complete avoidance of the health care system by some women.

The lack of communication and collaboration between health care providers, coordination of care, continuity of carer and the absence of choice around a woman's place to give birth, were identified by workshop participants as the most critical aspects of the health service requiring improvement. [25].

## **1.2 Objectives of the Study**

### **1.2.1 Primary objective**

To investigate the quality of MIH services and their use at the primary and referral level, by remote dwelling Aboriginal mothers and their infants in the Top End of Australia.

### **1.2.2 Secondary objectives**

To document the burden of disease in this population.

To identify the barriers to quality health service delivery for remote dwelling Aboriginal mothers and infants.

### **1.2.3 Specific objectives**

1. To measure clinicians' adherence to local guidelines for ANC and the follow up of identified problems, as a measure of the quality of care.
2. To measure clinicians' adherence to local guidelines for growth faltering and anaemia and follow up of identified problems in infants, as a measure of the quality of care.
3. To identify barriers to the quality health service delivery for Aboriginal mothers.
4. To identify barriers to the quality health service delivery for Aboriginal infants.
5. To describe the patterns of health service utilisation by Aboriginal mothers at a remote health centre (RHC) and regional hospital during pregnancy, birth and the postpartum period.
6. To describe the patterns of health service utilisation by Aboriginal infants at a RHC and regional hospital during their first year.
7. To document the burden of disease among Aboriginal women during their pregnancy, birth and the postpartum period.
8. To document the burden of disease among Aboriginal infants during their first year.

## **1.3 Study Significance**

The intention of this research was to produce a thesis and related publications that provide pragmatic information that is useful to the remote communities themselves, the

health providers, and the policy makers and government who guide and plan the health services used by these remote dwelling families in the NT.

This study is aligned with NT government priorities for improving health care for mothers and infants in remote communities [51] and the NHMRC Road Map for improving Aboriginal health through research [52]. Improving MIH has also been an identified priority area by the participating communities themselves [25].

There has been a lack of good quality longitudinal data about Aboriginal mothers and their infants [53]. A key step towards reducing disparities in Aboriginal health outcomes is to begin by establishing baseline data on these outcomes, particularly in remote Australia [54]. This study has responded to this identified need by providing baseline data on linked remote dwelling Aboriginal mothers and infant pairs from two of the largest Aboriginal communities in the NT, across the continuum of care.

Understanding barriers faced by Aboriginal families to health care access is vital to reducing inequity in, and improving quality of, care [55]. It is also essential that the barriers faced by clinicians when delivering effective health service be understood. These barriers remain unclear and have been investigated in this study, predominantly at the PHC level to help address this knowledge gap. International evidence proposes that 'as part of a multi-pronged approach (to improving health), the delivery of comprehensive health care for sustained period of time is essential if Aboriginal and Torres Strait Islander health outcomes are to be improved' [33, p56]. There has been little focus given to exploring how pregnancy, birth, the postpartum period and infancy in remote communities might be better supported by PHC services.

Available data suggests Aboriginal women are less likely to attend mainstream health services, commence ANC later in pregnancy and attend for fewer visits compared with non-Indigenous women [27, 56]. Much anecdotal evidence also exists among clinicians in the NT to suggest that Aboriginal women and their infants do not regularly attend health services and this was one of the reasons for their poor health outcomes; however there was an absence of published data from the communities and hospitals to confirm this.

There is much literature describing different maternal health services for Australian Aboriginal women, often reported in the context of a program evaluation. Service use is



frequently reported in urban and rural services [57-72] and predominantly focuses on the AN period. Fewer studies have been identified that address maternal health service use by remote dwelling Aboriginal women [8, 20, 27, 31, 66, 73]. There was a scarcity of studies that reported on maternal hospital admissions during the AN period [31, 59] and infant admissions to the neonatal nursery [59]. No studies were identified that investigated PN health service use by remote dwelling Aboriginal women at the primary and referral levels.

The dearth of comprehensive data on Aboriginal MIH service use has been identified in the literature [74]. This research undertakes a comprehensive investigation of health service use from the first contact during pregnancy until six months postpartum for the mother and one year for the infant at both the RHC and hospital.

Studies that have investigated the quality of ANC provided to remote dwelling Aboriginal women have generally drawn their data from one source: either the hospital or the RHC medical record [27,31, 75].

I identified early in the pilot stage of data collection that hospital records of these women were often incomplete, as the documentation and records of pregnancy care undertaken in RHC were sometimes missing. Similarly, RHC records were also incomplete as women had information documented in their hospital record during an AN visit or hospital admission, but this information was not always transferred to the RHC for inclusion in the woman's record. Most remote dwelling women in the Top End use maternal health services at both the hospital and HC during their pregnancy and birth. Therefore it was necessary to cross check and use both hospital and RHC medical records in this study to ensure complete and accurate data collection.

The scoping workshop described elsewhere [25] identified poor communication between health providers at the regional hospital and RHCs. There was a clear lack of shared understanding by clinicians working in remote areas and the hospital about the way health services function in each site, particularly around the processes undertaken by women and infants to access services, the way care is transferred across the sites and the implications of this upon the quality of service delivery.

There is a lack of published evidence to guide policy makers in designing this transition across services, particularly in remote settings. Few studies have investigated the

consequences of health service design for remote dwelling Australian Aboriginal mothers and their infants (8, 20, 23) and there is little known about the 'journeys' undertaken by remote dwelling mothers and infants through the health system (21). This study investigates the transitions of care across remote and referral services and the impact of these transitions on quality of care, specifically in the postpartum period, for the first time.

Studies describing health service use by remote dwelling Aboriginal infants [18, 76] and the quality of health service delivery [77-79] are limited. Most studies on hospital use describe admissions by urban and remote Aboriginal children aged less than 5 years [80-86] and often restrict their data collection to specific disease types, such as diarrhoeal or respiratory infection. One study reported patterns of hospital admission by children from remote NT communities [87]; however data was from the mid-1970s-80s.

One study investigated use of remote primary health clinics by children under 5 in East Arnhem communities [76], although only data on presentations for infectious reasons were reported whereas this study investigated all reasons for infant health service use, including acute reasons, well baby checks, social reasons and review visits. I also report on hospital admissions from birth, by these same infants during their first year. No previously published study was identified that had investigated all reasons for remote dwelling Aboriginal infant health service use at the remote primary and referral levels.

Knowing how, when and where services are used, their quality and the barriers to their effective delivery helps us to better understand and respond to the needs of the workforce and the families who use these services at the primary and referral level. This research contributes to the evidence base for recommendations to community members, clinicians, health planners and policy makers, so that appropriate health service improvements can be developed to deliver effective, equitable and efficient MIH services to remote dwelling NT Aboriginal families.

## **1.4 Research Approach**

A Continuum of Maternal and Infant Care (COMIC) assessment framework informed the data collection. This framework, based upon a situational analysis methodology [88],

incorporated mixed methods to achieve the research aim. These methods included a retrospective cohort study, semi-structured interviews and observational data collection. The data was conceptually linked through a health care quality improvement technique called Patient Journey Modelling [89]. This technique was used to map processes of patient movement through a health care system, analysing how efficiency can be improved by removing wasted or duplicated activities and safety increased through better continuity and communication between the patient and the clinician.

## **1.5 Ethics**

Ethics approval was obtained from the Human Research Ethics Committee of the Menzies School of Health Research and the NT Department of Health and Families (DHF) (07/49: 2007) and ratified by the University of Sydney (12875: 2010). Additional ethical approval to undertake fieldwork in the remote communities was obtained from the community health boards and local councils.

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## **2 LITERATURE REVIEW**

### **2.1 Overview**

This chapter is divided into three major sections. The first section provides background information about the region in which this study was undertaken – the ‘Top End’ of the NT. The description of the location and climate, the demographics and health services, with a focus on MIH, provides important key contextual information for the research that is reported in Chapters 4 and 5.

The second section summarises the pregnancy and birth outcomes for Aboriginal and Torres Strait Islander women and the outcomes for their infants during their first year, with a focus on NT and remote dwelling populations. The third section presents a review of the use of MIH health services by Aboriginal mothers and their infants and the quality of services provided to this population will also be described.

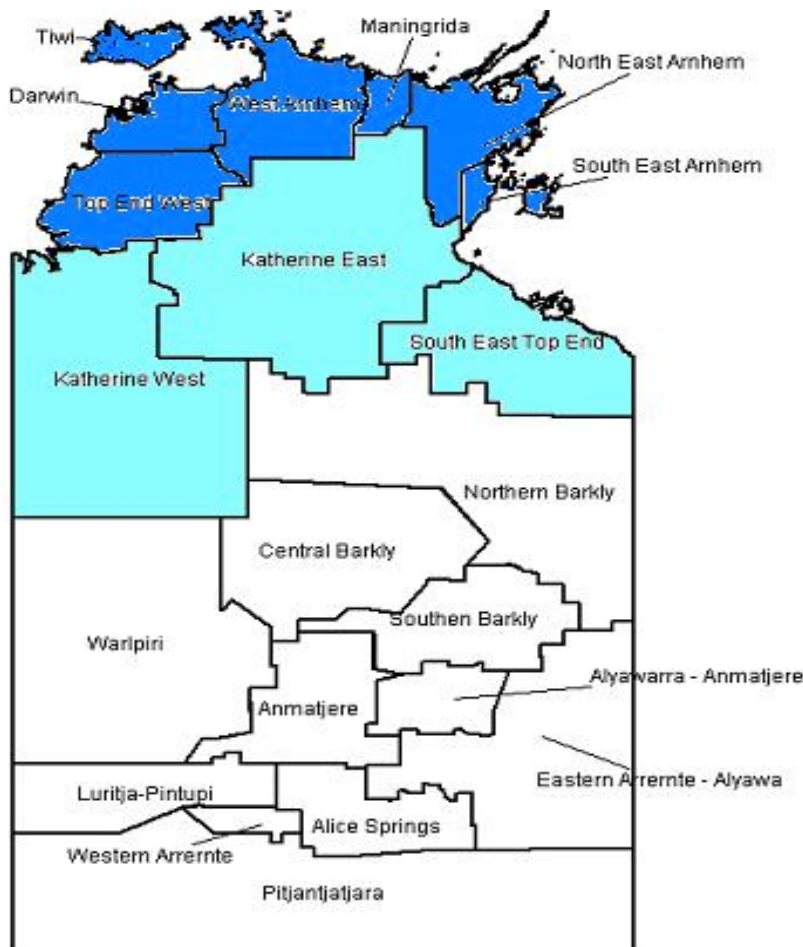
### **2.2 The Research Setting: The ‘Top End’ of the Northern Territory of Australia and Its People**

Australia is a large country that lies southeast of Asia between the Pacific and Indian oceans. The country spans a total area of 7,686,850km<sup>2</sup> with a population of 22.62 million people who live in diverse locations from modern metropolitan cities, to isolated locations in the desert [1].

Australia is becoming progressively urbanised with more than two thirds of the population now concentrated in major cities and the remainder living in regional or remote areas [1]. There were 548,370 people who identified as Indigenous (Aboriginal or Torres Strait Islander) counted in the 2011 census [2], which equates to around 2.5% of the total population. Most Indigenous people live in regional areas (43%) and major cities (30%) across the country with one quarter residing in remote areas [3].

The NT extends across one sixth of Australia yet has only 1% of its population. In 2010, this was estimated to be approximately 229,700 people [4]. The northern half of the NT is referred to as the ‘Top End’. It has three main urban centres: Darwin, Katherine and

Nhulunbuy (Figure 1). Most of the population reside in the greater Darwin area that includes Darwin, Palmerston, and Litchfield (55%) and in Alice Springs (18%) [5]. The median age of the NT population is 31 years, the lowest median age of all states and territories in Australia, compared with the national average of 35 years [6]. The Aboriginal population is comparatively young with a median age of 22 years [7].



**Figure 1: Northern Territory Health Zones** (Top End health zones highlighted in aqua and blue)

**Source:** Zhao Y, Paice J, Murtagh D, Lee H and Guthridge S. Population Estimates for Indigenous Health Zones in the Northern Territory. Department of Health and Community Services, Northern Territory 2007

### **2.2.1 Darwin**

Darwin is the capital city of the NT, located in the Top End, with a population of 127,500 people [4]. Ten per cent of this population are of Aboriginal or Torres Strait Islander descent, representing the highest proportional population of Aboriginal people in any Australian capital city [4]. The traditional owners of the urban Darwin area are the Larrakia people.

Darwin is the largest city in the NT, but the least populated of all the capital cities in Australia. It is situated on the Timor Sea and is an important access route for Indonesia and East Timor.

### **2.2.2 Climate**

The Top End region of the NT has a tropical savannah climate with two distinct wet and dry seasons. From November to April, monsoon rains, tropical cyclones and high humidity characterise the wet season, with an average humidity of 70% during the wettest months [8]. Most of the rainfall in the region occurs from December–March. The temperature does not vary greatly during the year, with an average maximum temperature of 32 degrees Celsius. During the dry season, May–October, humidity is low, rainfall is minimal and the days are warm and sunny [9].

### **2.2.3 Remote Northern Territory**

There are in excess of 100 different Aboriginal languages and clan and kinship groups throughout the NT [7]. In stark contrast to other regions of Australia, Aboriginal and Torres Strait Islander Australians comprise 30% of the NT population [10-11] with 81% residing in remote or very remote communities [12] and on their outstations or homelands. These discrete Aboriginal communities are widely dispersed across the NT and range in size from a single family to a few thousand people [13]. A discrete Aboriginal or Indigenous community is defined as ‘a geographic location, bounded by physical or cadastral (legal) boundaries, and inhabited or intended to be inhabited predominantly by Indigenous people, with housing or infrastructure that is either owned or managed on a community basis’ [14].

In the 2001 Community Housing Infrastructure Needs Survey, there were 632 discrete, populated Aboriginal communities across the NT, with 21 health zones designated to improve local planning, governance and coordination of health services [15].

#### **2.2.4 Defining remoteness**

The classification of a community as 'remote' or 'very remote' was originally made using the Accessibility/Remoteness Index of Australia (ARIA) [16], which has now been superseded by ARIA+ [17]. The Index relies on a geographical method to define remoteness and measures access based on the road distance to service centres that are considered to be typically available in metropolitan areas of the country [17]. There are five categories of service centres, classified by populations of:

1. more than 250,000 persons
2. 48,000 to 249,999 persons
3. 18,000 to 47,999 persons
4. 5,000 to 17,999 persons
5. 1,000 to 4,999 persons.

The ARIA+ index is a continuous variable with values assigned (0–15) to represent the degree of remoteness. The calculation of the value is made as follows:

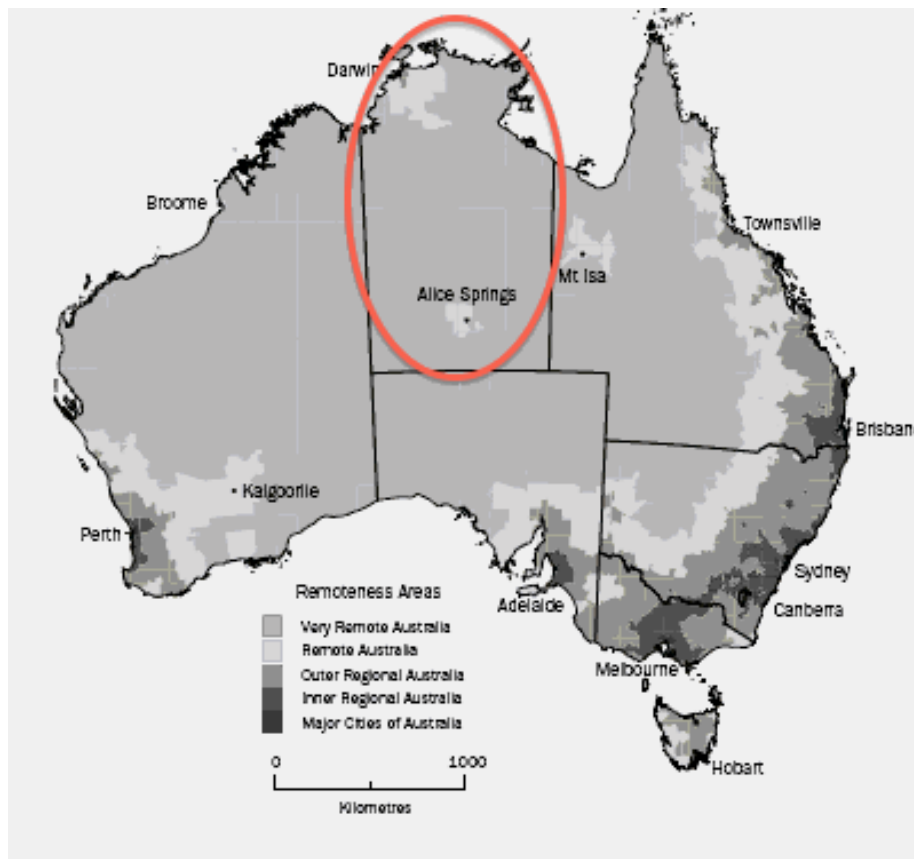
'For each locality, the distance to each of the five categories of service centre is converted to a ratio to the mean. To remove the effect of extreme values, a threshold of 3 is applied to each component and then the five component index values are summed. This produces a continuous variable with values between 0 (high accessibility) and 15 (high remoteness). Index values for an expanded locality and point database of 42,648 localities are then interpolated to produce an index value for 1km grids and averages calculated for larger areas such as postcodes [17, p17].

The index values are also grouped into five categories:

1. Major cities of Australia
2. Inner regional Australia
3. Outer regional Australia
4. Remote Australia
5. Very remote Australia



In this thesis, two of the study sites are NT communities that are classified as ‘Very remote’ and the regional centre, Darwin, is classified as Outer regional (category 3). The ARIA+ areas in Australia can be seen in Figure 2 with the circle highlighting the NT.



**Figure 2: ARIA+ areas of Australia**

Source: Glover J, Tennant S. 2003 Remote Areas Statistical Geography in Australia: Notes on the Accessibility/Remoteness Index for Australia (ARIA+ version). Working Paper Series No. 9. Public Health Information Development Unit, Adelaide, 2003

As in other parts of Australia, Aboriginal and Torres Strait Islander people are socially and economically disadvantaged compared to non-Indigenous people [18] and this disadvantage increases with remoteness [17].

## **2.2.5 Northern Territory remote communities**

### **2.2.5.1 Housing and infrastructure**

There is variability in the quality of housing, extent of infrastructure and employment opportunities across the remote communities. Poor quality housing however is common. The 2002 National Aboriginal and Torres Strait Islander Social Survey found that 58% of remote dwelling Indigenous people lived in homes that had major structural faults and were in need of repair (e.g. rising damp or major cracks) [19]. The NT reported the highest rates of overcrowding in Australia [38%] [20], with an average occupancy of 8.8 people per dwelling in remote communities [21]. Overcrowding tends to worsen when there is a temporary increase in the community population. Twenty-one per cent of individual remote and very remote communities experienced temporary population increase throughout 2005, lasting for more than two weeks at a time. Fifty-three per cent of the temporary population increase reported was due to cultural reasons or with the arrival of holiday visitors [21]. However it also commonly occurs throughout the wet season when families leave their homelands as can be completely cut off from road access, health services and other infrastructure for months at a time.

Access to sewage, water and electricity supplies are often problematic and not the same quality as in major urban centres. Failure of electricity supplies and sewage systems are common [22-23]. Only 41% of large communities (>50 people) were connected to a town water supply but the quality of drinking water was poor for almost a third of all communities [22-23]. Organised rubbish collection and disposal does not exist at all in a small number of communities [23].

### **2.2.5.2 Transport and communication**

#### **Road and flight access**

Flooding often occurs during the wet season, preventing road access into and out of many remote communities. Airstrips for commercial and/or emergency medical aircraft are common in many larger communities; however extreme weather conditions that include storms and cyclones can delay or prevent aircraft from being able to reach these areas. A number of communities have only limited air access year round and fewer island communities have part or no air access [24]. In the NT, the cost of a one hour

return commercial flight from Darwin to one of the study field sites is approximately \$500 Australian dollars [25], which for many Aboriginal families from these communities is prohibitive.

### **Communication**

Telephone access is a vital communication need in remote communities for accessing emergency and government services and for maintaining personal contact with family and friends. Most remote communities have at least one working public phone [24]. Mobile phone coverage in remote communities is improving but during the data collection period there were often black outs. Government funding is currently being used to upgrade and improve public and mobile phone and Internet access across remote communities [26].

#### **2.2.5.3 Employment**

Opportunities within remote communities to enter skills-based training or mainstream employment are limited [27]. Across Australia, Indigenous people have higher rates of unemployment and are more likely to be employed in low skilled jobs than non-Indigenous people [28].

#### **2.2.5.4 Education**

A key antecedent to gaining employment is strong numeracy and literacy skills. Among year five (approximately 10 year old) remote dwelling Indigenous students, 33% achieve the numeracy benchmark compared with 78% of urban-based Indigenous students. In regards to grammar and punctuation, remote dwelling Indigenous students are the lowest performing of all students, with only 24% of year three (eight year old) students and 20% of year five students reaching the national benchmark. Similarly, reading standards are considerably worse for these students with only 30% of year three and 22% of year five students attaining the national reading benchmark. School retention rates among Indigenous students decline significantly throughout the secondary school years, with only 43% of students continuing from year seven through to year 12 [28].

A high turnover of teaching staff, racism, a limited curriculum applicable to Indigenous culture, a lack of understanding of Indigenous ways of learning and educational needs, and underservicing and underfunding of schools are among the factors contributing to the educational disadvantage experienced by Indigenous students [29-32]. Student factors that affect academic achievement relate to low birth weight, adolescent pregnancy, drug and alcohol use, speech and learning difficulties [33-34]. Family factors such as the lower value placed upon western education, socioeconomic status and family violence also exacerbates this situation as does intergenerational low literacy [30, 35] and significant government cuts to funding for bilingual education.

In remote areas of the NT, these issues are compounded by the geographical isolation of students from schools, which often means that students have to leave their home communities and families to attend boarding school (particularly for secondary schooling), opt for distance education or they may opt not to pursue these alternatives and fail to complete school [36].

#### **2.2.6 Government response to the situation in remote Northern Territory communities**

In 2007, the 'Ampe Akelyernemane Mele Mekarle, Little Children are Sacred: Northern Territory Board of Inquiry into the Protection of Aboriginal Children from Sexual Abuse' report [37] was released, which, like numerous other reports from the past 30 years, reiterated the appalling health outcomes of Aboriginal people as well as the high levels of family violence, alcohol abuse and poor educational attainment of children and young adults. It stressed the ongoing issues in remote communities of 'people without meaningful things to do, failure of service methodologies, dysfunctional governance and overcrowded houses' [38, p10]. The report emphasised 'that child abuse and neglect in Indigenous communities throughout the NT was at crisis levels' [38, p6].

In response to this report, the then Australian Prime Minister, John Howard, and the then Minister for Families, Communities and Indigenous Affairs, Mal Brough, launched a highly controversial 'Northern Territory Emergency Response' (NTER) that aimed to 'protect children and make communities safe in the first instance, and then to lay the basis for a sustainable future for Indigenous people in the Northern Territory' [38, p6]. Many contentious interventions were rapidly implemented in remote communities,

without prior engagement or input from Aboriginal people or the communities themselves. These interventions included:

- 'Introducing widespread alcohol restrictions on Northern Territory Aboriginal land;
- Introducing welfare reforms to stem the flow of cash going toward substance abuse and to ensure funds meant to be for children's welfare are used for that purpose;
- Enforcing school attendance by linking income support and family assistance payments to school attendance for all people living on Aboriginal land and providing meals for children at school at parents' cost;
- Introducing compulsory health checks for all Aboriginal children to identify and treat health problems and any effects of abuse;
- Acquiring townships prescribed by the Australian Government through five year leases including payment of just terms compensation;
- As part of the immediate emergency response, increasing policing levels in prescribed communities, including requesting secondments from other jurisdictions to supplement Northern Territory resources, funded by the Australian Government;
- Requiring intensified on ground clean up and repair of communities to make them safer and healthier by marshaling local workforces through work-for-the-dole (government financial support for unemployed);
- Improving housing and reforming community living arrangements in prescribed communities including the introduction of market-based rents and normal tenancy arrangements;
- Banning the possession of X-rated pornography and introducing audits of all publicly-funded computers to identify illegal material;
- Scrapping the permit system for common areas, road corridors and airstrips for prescribed communities on Aboriginal land; and
- Improving governance by appointing managers of all government business in prescribed communities' [39].

In 2009, the Prime Minister and the Chief Minister of the NT signed the 'Closing the Gap Northern Territory National Partnership Agreement' [40]. This agreement built on the NTER to further:

- 'Ensure the protection of women and children;
- Reduce violence and improve family and community safety;
- Improve the quality of education, increase school participation and employment outcomes;
- Improve health and wellbeing, particularly that of children;
- Promote positive behaviours among Indigenous youth; and
- Promote personal responsibility' [40, p9].

As a result of this agreement, a multitude of initiatives to improve MCH health outcomes and service were also implemented in the NT under the 'Closing the Gap' agreement with additional federal funding [40-45].

Key initiatives included:

- The establishment of midwifery group practices in Darwin and Alice Springs
- Expanding the numbers of outreach midwives, remote based Aboriginal community workers and child protection workers
- Introduction of remote-based designated midwives and child health nurses (CHNs)
- Introduction of Adolescent Health Promotion Workers to provide community-based sexual and reproductive health for adolescents and improve access to parenting and AN education for young families
- Expansion of community-based and culturally appropriate ANC programs and school-based parenting education
- Expansion of the number of *Strong Women Strong Babies Strong Culture* program workers and coordinators
- A home nurse visiting program for Aboriginal children and families to provide family support
- Dental and other specialist follow-up services for children identified with problems in the health checks undertaken as part of the NTER
- Establishment of community-based early childhood centres and family centres

- A mobile counseling service for children and families affected by abuse or neglect.

Many of these initiatives are still being rolled out in 2013 when this thesis was written.

## **2.3 The Aboriginal and Torres Strait Islander Definition of Health**

Aboriginal people perceive health through a multidimensional worldview that does not solely relate to physical health and the absence of disease [46]. It comprises a whole-of-life view and holistic approach that includes an individual's social, emotional, cultural, spiritual and wellbeing, together with community capacity and governance [47]. The delivery of health services to Aboriginal and Torres Strait Islander peoples should clearly be more than just a clinical service. It is critical that this holistic approach, that is consistent with the World Health Organization (WHO) model of Primary Health Care [48], is integrated into the planning and delivery of health services in order for these services to be effective, appropriate and acceptable to Aboriginal and Torres Strait Islander peoples.

## **2.4 Health Status of Aboriginal and Torres Strait Islander Peoples**

### **2.4.1 The colonisation of Australia: The impact on Aboriginal and Torres Strait Islander peoples**

The Aboriginal and Torres Strait Islander peoples are the first inhabitants of Australia, having lived in the country for more than 60,000 years [49]. European colonisation of Australia began in 1788, rapidly leading to detrimental consequences for the Aboriginal and Torres Strait Islander population with the introduction of diseases such as small pox, tuberculosis, influenza and measles that decimated this population. Aboriginal and Torres Strait Islander people, who prior to European occupation had lived a traditional nomadic family lifestyle, were taken from their traditional homelands and culture to live in overcrowded missions, reserves and stations and experienced contact with infectious disease, poor diet and inadequate health care. Imported diseases and poor environmental health standards continue to persist as major contributors to the health disadvantage of Aboriginal and Torres Strait Islanders [50].

Access to a traditional diet was lost on the missions and instead replaced with imported food rations based on tea, flour, alcohol, tobacco and sugar. Poor nutrition has significantly affected the levels of chronic disease and poor dental health in this population [50].

People removed from their traditional homelands to live on the missions as part of Australia's 'Protection' (segregation) policy often had their family structures and groups abolished [50]. Children who were of 'mixed race' were forcibly removed from their families and made to live in homes whereby they would be taught the European way of life. It was thought that 'full-descent' Aboriginal people would die out, and those of 'mixed-descent' would merge with the non-Aboriginal population over time [50].

The segregation policy failed and was replaced by policies encouraging Aboriginal people to 'assimilate' and 'integrate' into white Australian culture by abandoning their own culture. Australian legislation maintained separate rights, wages, education, welfare and a health care system for Aboriginal peoples up until the last few decades. It was only in 1967 that a referendum was held and Aboriginal people gained the right to be called citizens of Australia. As 'mainstream' systems changed to include Aboriginal peoples, inadequate attention was given to ensuring that these systems met the needs of Aboriginal peoples [51].

Aboriginal peoples continue to be the most disadvantaged group in the country. In many communities, particularly those in remote areas, many still do not have access to adequate housing, roads, water and power supplies and sewage, contributing to their high burden of illness [52].

Generations of Aboriginal and Torres Strait Islander peoples have experienced enormous grief caused by the forced dispossession of their land, the legislated removal of their children and interference with their culture and communities. This has significantly contributed to 'ongoing problems in emotional, spiritual, cultural and social well-being for Aboriginal and Torres Strait Islander individuals, families and communities' [50, p6].



### **2.4.2 Health outcomes**

Australia is considered to have one of the finest health care systems in the world [53]. Aboriginal people, however, have dramatically worse health outcomes than non-Aboriginal people by every measure, and this is as true for children as it is for adults [54]. Health outcomes for Aboriginal people in remote communities tend to be worse than those in larger cities [52]. Compared with other Indigenous populations, such as the Maoris of Aotearoa and the native people of the United States and Canada, the health statistics of Australia's Indigenous population shows they fare much worse [55].

The highest burden of disease and fatal disease and injury among all states and territories in Australia exists among the Aboriginal population in the NT [56]. A higher prevalence of health conditions – including notifiable communicable diseases, kidney disease and diabetes, rheumatic heart disease, hypertension and ear and hearing problems – are experienced by Aboriginal people [57], as are rates of mental illness, intentional self-harm and substance abuse [58].

Life expectancy is substantially below that of other Australians. For Aboriginal males, this was estimated to be 67.2 years for males compared with 78.7 years for non-Aboriginal males. For females, this was estimated to be 72.9 years compared with 82.9 years for other Australian females [59]. Mortality outcomes vary between jurisdictions across Australia. The lowest is in the NT where the median age at death for Aboriginal people was 50.8 years for males and for 55.4 years for females [60]. These are in stark contrast to non-Indigenous Australians and lower than in many developing countries.

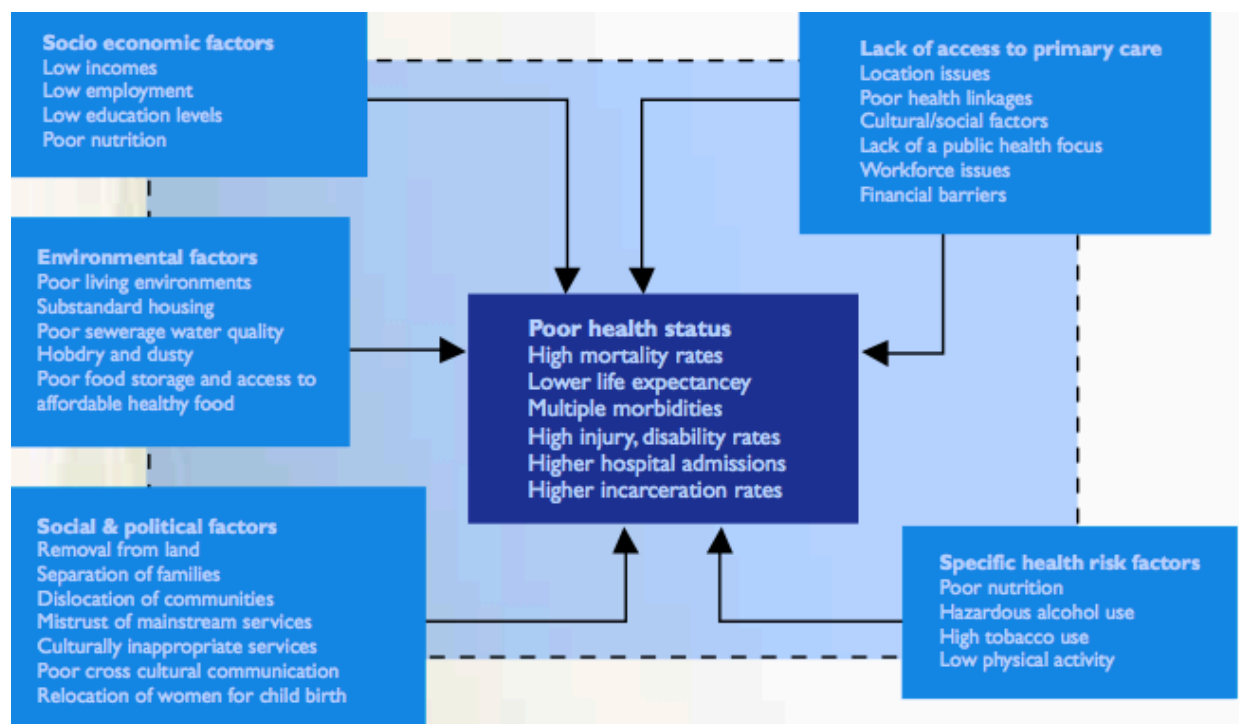
In 2009, the primary cause of death for all Australians (Aboriginal and non-Aboriginal) was ischaemic heart disease. Among Aboriginal people, the next most common cause of death was diabetes, followed by suicide, cancer and stroke for males and chronic lower respiratory diseases and stroke for Indigenous females [61].

## **2.5 Social Determinants of Health**

There is significant evidence that an individual's socioeconomic and cultural circumstance impact upon their health and wellbeing [62]. In Australia during the first half of the 20<sup>th</sup> century, improvements made to living conditions and the physical environment led to a significant development in the health status of the population.

However, these same improvements have not been made in many Aboriginal communities, especially in remote areas, hence the potential to attain good health outcomes have not been achieved [63].

Aboriginal families have substantially lower incomes, employment, home ownership and educational attainment compared with non-Aboriginal families [63]. These families also suffer disproportionately from overcrowding in poor quality housing; particularly in remote areas, with the number of people per house reported as high as 33 [64]. Houses also often lack appropriate environmental health infrastructure [63]. The effect of social and environmental factors on health and associated risk behaviours is illustrated in Figure 3.



**Figure 3: Factors impacting upon Aboriginal and Torres Strait Islander health status – Interactions of social and physiological determinants of health**

**Source:** National Aboriginal and Torres Strait Islander Health Council. National Strategic Framework for Aboriginal and Torres Strait Islander Health 2003–2013: Context. Canberra: NATSIHC, 2003: p10.

Overcrowded housing is associated with poor health [64-65] with its main effect upon children [66], resulting in higher rates of infectious diseases such as respiratory, skin and ear infections [64, 66-67]. Recurrent and persistent infections in children can affect growth and development [68]. Among adults living in overcrowded houses, in addition to respiratory and skin infections, higher rates of trachoma [69], alcohol abuse and social problems have been described [70]. Tuberculosis, a classic disease of poverty and overcrowding [71], is largely controlled in Australia but persists in remote communities [72]. Poor sanitation has been associated with diarrhoea, parasites and childhood anaemia and poor water quality with urinary tract infections [69].

Access to health care is an important determinant of health [73]. Drawing on international evidence, maternal education has been shown to improve child survival [74] and the use of maternal [75-77] and child health services in a number of countries [78-79]. There is also evidence that correlates higher education and income with lower drug and alcohol use among Aboriginal people [80]. Poor MIH is linked closely with the early onset of adult chronic disease [81], which makes maternity care and early infant care a vital preventive strategy. In recent years, there has been an increasing acknowledgement of determinants such as social exclusion [82], racism [83-84], control over one's life circumstances [85] and cultural differences [86] and their impact upon health. Research by Paradies [83-84] confirmed that Indigenous people who experience racism have poor physical and mental health outcomes.

Each determinant of health addressed here does not act in isolation. Comprehensive and culturally appropriate strategies are therefore needed that recognise the causality and complexity of the multifaceted interactions that impact upon the lives of individuals and their communities.

## **2.6 Health Outcomes of Aboriginal Mothers and Infants**

This section presents health outcomes for Aboriginal mothers and infants. There is limited data specifically reflecting outcomes for remote dwelling women or infants in the NT, as this data is not usually available based on locality or residence. Where available, data is presented for mothers and infants in remote communities and in the NT; otherwise data is aggregated for all Aboriginal women and infants. Given the evidence that health outcomes are generally worse for remote dwelling Aboriginal

people, it would be useful to have maternal and infant data reported by locality to identify specific health needs of the remote population and potential gaps in service delivery.

### **2.6.1 Number of births**

In 4% of all births registered in Australia in 2010 (n=16,129) one or both parents identified as Indigenous [87]. This underestimates the true number of births as Indigenous status is not always reported and there is sometimes a delay in birth registrations. During the period 1996–2005, 36% of all births in the NT were to Indigenous women [88].

### **2.6.2 Maternal age at birth**

Indigenous mothers have more babies and give birth at a younger age than non-Indigenous mothers in Australia [87]. In 2010, teenagers accounted for 20% of babies born to Indigenous mothers compared with 4% of babies born to all mothers [87]. Indigenous mothers gave birth at a median age of 24.6 years compared with 30.7 years for all other mothers [87].

In the NT, the average age of first time Indigenous mothers was 19.4 years; almost eight years younger than non-Indigenous mothers (27.5). The total fertility rate of Indigenous women declined over the 1996–2005 period, from 2.5 to 2.4, and compared with 1.9 for non-Indigenous women [88].

### **2.6.3 Pregnancy outcomes and maternal health**

#### **2.6.3.1 Pregnancy**

Australia is a wealthy, developed country and considered to be one of the safest in the world to give birth [89]. Despite this, there are extraordinary disparities in pregnancy and birth outcomes between Aboriginal and Torres Strait Islander women and other Australian women, reflected in the higher rates of preterm birth (13.3% vs. 8.0%), low birth weight (12.4% vs. 5.9%) and perinatal death (17.3 vs. 9.7 per 1000 births) [90]. Over the past twenty years, little progress has been made in the reduction of these outcomes, apart from perinatal mortality [91].

Smoking is a major risk factor for preterm birth, low birth weight, stillbirth and sudden infant death syndrome. In 2005, 52% of pregnant Aboriginal and Torres Strait Islander women smoked (including those in the NT), compared with 16% of all other pregnant Australian women [92]. There is good evidence for the effectiveness of smoking cessation interventions during pregnancy [93] that can be provided through ANC. Research in Queensland and Western Australia identified that most perinatal deaths among Indigenous babies were attributed to AN factors that could be addressed through targeted primary health care interventions, such as smoking cessation programs, to reduce the prevalence of low birth weight and preterm birth [94].

There are numerous medical conditions in pregnancy that impact upon Aboriginal women and their infants disproportionately when compared with other Australians. Neural tube defects have been reported at higher rates among Indigenous women and those living in remote areas, compared with other Australian women [95]. Folate supplementation is known to be effective in reducing the prevalence of these defects [96].

Anaemia is detected in approximately 12% of Australian pregnant women [97]; however higher prevalence rates of anaemia [26–34%] have been frequently reported in Aboriginal and Torres Strait Islander women's pregnancy [98-99], suggesting that nutrition may be compromised. Poor access to healthy, affordable food is common in remote areas of the NT and socioeconomic factors have a strong influence on purchasing patterns and food intake [100]. In the NT, 8% of Aboriginal women were diagnosed with gestational diabetes and 11% hypertensive disorders compared with 6% and 10% among other Australian women, respectively [88]. Both conditions can impact upon infant growth outcomes [99, 101].

Genital or urinary tract infections that remain untreated during pregnancy contribute to preterm birth and/or newborn sepsis. Urinary tract infections (UTIs) [98,102] are highly prevalent, with Australian studies reporting rates of 15–20% for UTIs among Aboriginal women in northern Australia, which is 5–10% higher than reported in other international studies [103-104]. Similarly, sexually transmitted infections (STIs) have been reported at rates of 4% [105] to 20% [106] among pregnant Aboriginal women in northern Australia. Early onset Group B Streptococcus (GBS) occurs at more than three

times the rate among Aboriginal babies compared to non-Aboriginal babies [106], with good evidence existing for the use of intrapartum antibiotics to reduce neonatal GBS infection and antibiotics for eradicating STIs and UTIs, which also act to reduce the incidence of low birth weight [103,107-110]. The screening and treatment of these conditions can be provided through high quality ANC and targeted interventions including contact tracing and appropriate treatment and follow up to ensure there has not been reinfection.

#### **2.6.4 Birth**

During 2001–2005, an analysis in the NT compared non-Indigenous mothers with Aboriginal and Torres Strait Islander mothers. The study showed they:

- were four times more likely to give birth outside of a hospital, usually in a RHC (4.8% vs. 1.2%), and of the non-Indigenous mothers, most of the out-of-hospital births were planned home births
- had lower rates of induction (16.4% vs. 24.0%)
- were less like to have an instrumental delivery (4.9% vs. 8.7%) or caesarean section (25.4% vs. 28.3%)
- were more likely to have an intact perineum (48.9% vs. 42.2%)
- were almost twice as likely to have a postpartum haemorrhage (11.7% vs. 6.5%)
- had a longer PN hospital stay (4.3 vs. 3.8 days) [88].

#### **2.6.5 Social and emotional health outcomes**

There is little known about the prevalence of perinatal depression or the experience of this among Aboriginal and Torres Strait Islander women or men [111]. Given the extent of the issue in the general Australian population (10–13% of women experience AN depression [112] and 14% PN depression) [113], and coupled with the fact that there are specific events that increase stress, fear, sadness and loneliness among Aboriginal women during pregnancy – such as removal from their home, family and culture for birth [98, 114] – it is very likely that perinatal depression is a significant issue affecting Aboriginal mothers and one that needs to be investigated further.

A project investigating PN depression amongst Indigenous mothers [115] identified 'high levels of daily hassles, problems in the family, history of depression and emotional

problems, financial insecurity, major life events, a history of physical and emotional abuse and relationship problems with a current partner' [115, p29]. There was a significant association identified between these factors and an increased risk of perinatal depression [115].

A number of different perinatal assessment tools are used across Australia, but none have been validated for use in remote dwelling Aboriginal women who do not speak English as their first language [99] and many remotes areas, including the study sites do not offer routine screening.

Aboriginal-controlled Community Health Services and Aboriginal medical services that provide culturally appropriate mental health services are developing programs and adapting existing screening tools to tackle these issues locally [116].

#### **2.6.6 Postpartum morbidity**

Most complications that lead to maternal morbidity and mortality occur during labour and birth, and the first two weeks following birth [117]. The main acute obstetric morbidities include haemorrhage, sepsis and pregnancy related hypertension, with uterine prolapse, vesicovaginal fistulae, incontinence, dyspareunia and infertility contributing to longer-term morbidities. These morbidities, which are often debilitating and potentially life-long, affect at least 18 million women around the world [118-119].

Pollock [120] describes a paucity of comprehensive data describing severe maternal morbidity in Australia and a lack of local monitoring systems in place to routinely capture this data. The Australasian Maternity Outcomes Surveillance System (AMMOS) has now been established, which collects data on rare or serious conditions during pregnancy. This provides an important source of surveillance data. The focus of the surveillance however is on severe morbidity and does not capture data in smaller maternity units with 50 births or less per year [121].

There is an absence of high quality data on postpartum outcomes and morbidity in remote dwelling Aboriginal women. This is critically needed – given the poor pregnancy and birth outcomes in this population and lower levels of health service access experienced by Aboriginal people [122] – to determine the burden of disease and to allow for strategic health care planning. Postpartum data that exists for Aboriginal

women is typically limited to mortality data [123]. Maternal morbidity data serves as a useful indicator for measuring not only health outcomes but also quality of care and service delivery [121], for which little data exists in Australia for services used by remote dwelling Aboriginal women.

## 2.6.7 Mortality

The maternal mortality ratio is more than two and a half times higher among Aboriginal women (21.5 vs. 7.9 per 100,000 live births) and known to be underestimated, as more than a quarter of cases did not include Indigenous status [123]. This maternal death report was not validated. Validation of the previous triennial report highlighted that around an extra 1/3 of deaths were not reported to the national committee. Although the numbers are small, a high proportion of maternal deaths occur in women from outer regional and remote and very remote communities [124] (see Table 1 below).

**Table 1: Distribution of births and maternal deaths in Australia by remoteness area of usual residence and Indigenous status**

| Australian region      | Maternal deaths     |                               |  |  | Distribution of births (%)                       |                             |                  | Australian population <sup>§</sup> (%) |
|------------------------|---------------------|-------------------------------|--|--|--|-----------------------------|------------------|--|
|                        | Number <sup>†</sup> | Distribution <sup>†</sup> (%) | Aboriginal & Torres Strait Islander <sup>†</sup> n | Aboriginal & Torres Strait Islander maternal distribution <sup>†</sup> (%) | Aboriginal & Torres Strait Islander <sup>†</sup> | Non-Indigenous <sup>†</sup> | All <sup>†</sup> |  |
| Major cities           | 58                  | 61                            | 3 <sup>‡</sup>                                     | 25 <sup>‡</sup>  | 27   | 71                          | 69               | 68                                     |
| Inner regional         | 14                  | 15                            |  |  | 19   | 18                          | 18               | 18                                     |
| Outer regional         | 15                  | 16                            | 5  | 42   | 26   | 9                           | 10               | 10                                     |
| Remote and very remote | 7                   | 7                             | 4  | 33   | 29   | 2                           | 3                | 2                                      |
| Not provided           | 1                   | 1                             |  |  |  |                             |                  |  |
| Total                  | 95                  | 100                           | 12   | 100  | 100  | 100                         | 100              | 100                                    |

Data from: <sup>†</sup>Maternal Deaths (direct, indirect, incidental and late) in Australia 2000-02[9]; <sup>‡</sup>Australia's Mothers and Babies 2006[10]; <sup>§</sup>ABS 2006 Census of Population and Housing[11].

<sup>‡</sup>Major cities and inner regional area amalgamated.

**Source:** Kildea S, Kruske S, Barclay L, Tracy S. 'Closing the Gap': How maternity services can contribute to reducing poor maternal infant health outcomes for Aboriginal and Torres Strait Islander women. *Rural and Remote Health* 2010; 10: 1383 (Online).



### **2.6.8 Health outcomes of Aboriginal infants**

Aboriginal infants have a higher burden of illness and hospitalisation than non-Aboriginal infants [125]. In the NT during 2001–2005, compared with non-Indigenous infants, Aboriginal and Torres Strait Islander infants:

- were almost twice as likely to be born preterm (14.8% vs. 7.5%)
- had a lower birth weight by 8% (3.111 kgs vs. 3.355 kgs)
- were more than twice as likely to be born low birth weight (13.5% vs. 6.2%) and
- had higher rates of fetal death (11.7 vs. 7.0) fetal and neonatal death (11.1 vs. 3.5) and perinatal death (22.7 vs. 10.5). The infant mortality rate for babies born to Indigenous mothers in the NT is currently the highest in the country [125].

Across Australia, the perinatal death rate is twice as high for Aboriginal babies relative to other non-Indigenous babies (17.3 per 1000 births vs. 9.7) [90]. Despite improvements in perinatal mortality since the 1990s [126], incidence rates of certain infectious diseases continue to be among the highest in the world [127-128], particularly in remote communities where there is a disproportionate burden of disease compared with the rest of Australia [129-132].

Among the most widespread health problems encountered by young Aboriginal children in remote communities are ear, respiratory and diarrhoeal and skin diseases and infestations [128-130, 133]. Skin diseases are endemic in many remote communities, with disease commencing early in life. Clucas et al. [134] reported that by age one, 69% of Aboriginal infants in East Arnhem communities in the NT were identified with skin sores and scabies, with the peak in the first presentation of skin disease occurring at around two months.

Respiratory infections – including tuberculosis, influenza and bacterial pneumonia and otitis media (middle ear disease) – are more common among children from northern and central Australia than for other Australian children [128,135]. Otitis Media in developed countries is around 5% during childhood; for remote dwelling Aboriginal children the prevalence reported is from 40–72%, with more frequent episodes of ear disease experienced by younger children [136-137] and onset generally occurring in the first three months of life [138-139].

Respiratory and diarrhoeal diseases are the leading causes of hospitalisation for Aboriginal infants and children [140]. Diseases that are not typically experienced by other young populations in Australia and more aligned with those found in developing countries, are reported in high rates among remote dwelling Aboriginal children; these include acute rheumatic fever [141-142], gonococcal conjunctivitis [143], acute post-streptococcal glomerulonephritis [144], trachoma and intestinal parasites [128, 130-133, 145]. This high burden of illness commencing in infancy foreshadows the early onset of chronic disease in adulthood [146].

Growth and nutritional problems are also commonly reported [147-149]. Across the NT, the rates of children who are underweight is decreasing but in remote communities, growth and nutrition still constitute a major health issue, with extraordinary levels of underweight (14.5%), stunting (11.3%) and wasting (9.0%) [147]. The expected prevalence of underweight in a healthy population is less than 2.5% [147]. Paterson et al. [150] identified that 39% of school-age Aboriginal children from remote communities were malnourished and 22% were anaemic, similar to Bailie et al. [151] who reported 35% of children (aged three months to five years) seen in NT remote communities had failure to thrive or growth faltering and 25% were anaemic. Specifically among remote dwelling infants, during 2004–2006, 12% were identified as underweight, 7% stunted, 9% wasting and anaemia prevalence was 34% [152].

Many of the factors contributing to the poor health outcomes experienced by remote dwelling Aboriginal infants arise from poor living conditions (such as overcrowding, inadequate water supply and sanitary facilities or household smoke exposure) and the interaction between other social determinants, such as low levels of parental education and unemployment [52], as previously described.

## **2.7 Maternal and Infant Health Services in the Top End**

‘Maternal, birthing and infant health services are core features of the free universal health services in Australia. The services vary across urban, rural and remote settings and are typically organised around AN, birthing, postnatal and early childhood periods. Service provision is highly dependent upon factors such as funding levels, composition, size and skill level of the workforce as well as infrastructure that is available to support such programs and linkages with other providers such as RHCs and hospitals’ [99, p16].

### **2.7.1 Urban community-based services**

Community-based ANC and PNC can be accessed in the Darwin urban area through general practitioners or obstetricians in private practice (for women who are able to pay for these services), the government-subsidised Aboriginal health services, including Danila Dilba and Bagot Aboriginal Community Health Service, home birth midwives or the Community Midwifery Practice.

Well baby assessments – including routine ‘check ups’ and education based around growth and development, infant feeding and nutrition, parenting and safety and childhood immunisations – are provided by CHNs in government-subsidised community health clinics. Fee-for service general practitioners or -paediatricians in private practice also provide child health care.

### **2.7.2 Home birth services**

Home birth services in the NT are provided free of charge under the auspices of the public health services in the NT DoH. Women are provided with AN, birth and PN care in their homes in a primary midwifery care model; however at the time of this research there was no system or infrastructure in place for home birth midwives to continue providing care to women at the regional hospital if they require hospital transfer. There are geographical boundaries for women who wish to have a home birth and these are limited largely to urban Darwin, and a formal appeal process for those who live outside of these boundaries to attempt to access this care [153]. Hence there is virtually no opportunity for women living in rural or remote communities in the Top End to access this model of care, despite this being a long standing request by women from these areas [7, 114, 154].

### **2.7.3 Hospital services**

The regional hospital in Darwin is the largest tertiary referral hospital in the NT, providing care for a population of approximately 140,000 people from across urban Darwin, remote communities in the Top End, Western Australia and Southeast Asia. The regional hospital has 363 beds and delivers medical care in all specialities, including operating theatres, and intensive care facilities for neonates through to adults [155].

The regional hospital is the only public hospital in Darwin that provides full-scope maternity (AN, birthing, PN) and paediatric services.

It is estimated that Aboriginal patients occupy up to 60% of the inpatient beds, with a high proportion of these patients in the maternity and paediatric units [156]. In 2005, of the 1300 staff employed at the hospital, less than 3% were Aboriginal [156]. At the time of writing this thesis there was no current data available to see if this has changed over time. The hospital has medical, midwifery and nursing students as well as obstetric and paediatric trainees. There have been long standing issues regarding recruitment and retention of staff [7], although this is improving [157] In 2006–2007, the average annual turnover of nurses and midwives was 35% [7]. In 2009, the turnover across all NT health services had declined to 30%. However, this is still very high, at double the rate of hospitals and health services interstate [157].

#### **2.7.4 Maternity care**

Antenatal clinics run Monday–Friday and include a midwives clinic and high-risk pregnancy clinic [7]. Approximately 1600 births take place at the hospital each year with a preterm birth rate of 15%. The 16 bed maternity unit provides AN, birth and PN inpatient care [158].

There are a number of different models of maternity care that are provided by the hospital. The Community Midwifery Practice is a midwifery led model of care that provides pregnancy, birth and PNC to low risk pregnant women, most of whom are non-Aboriginal and live in urban Darwin. The practice runs out of the Birth Centre at the hospital.

Common practice in the NT is for remote dwelling women to use a ‘shared care’ model for their pregnancy care, whereby the majority of the ANC is provided by RHC staff and some by hospital staff. Most women will transfer to the regional hospital at least once during their pregnancy for an ultrasound and AN appointment. Women are then transferred back to their home community for ongoing pregnancy until they reach 36–38 weeks gestation, when they are transferred once again to Darwin for the remainder of their ANC and to give birth in hospital.

Since the 1980s, it has become dominant practice for remote dwelling Aboriginal women to be relocated away from their community for childbirth. Prior to this, Aboriginal women birthed often at home or bush camps or sometimes at a community based health facility. During labour and birth traditional Aboriginal midwives and other women, usually those who had previously given birth themselves, and sometimes a nurse would support women. [Personal communication with HC manager, Community A. 4<sup>th</sup> August 2008]. It does not appear that NT policy was formally amended to cease community birthing and it is unclear why this was the case. However, given that maternal and infant mortality was high during this time, it could be assumed that this may have been part of the reason [159]. In the mid-1980s, the infant mortality rate in the NT was significantly higher among Aboriginal babies compared with non-Aboriginal babies (39 per 1000 live births vs. 10) [160].

When the women arrive in Darwin, they reside in hostel accommodation until the onset of labour and then give birth at the hospital, aided by care providers with whom they are generally unfamiliar [7]<sup>1</sup>. This causes considerable stress through cultural and social dislocation and separation from older children, and is likely to disempower the father and cause distress within the family [161]. The closeness and importance of fathers is often neglected in services provided to Aboriginal families; men need to be actively engaged to parent confidently [162]. Women are frequently without personal supports during this period as the cost of transporting family members is not subsidised by the government and is prohibitive for families on some of the lowest mean incomes in Australia [7, 10]. Following PNC in hospital women are discharged home if they live in Darwin. Remote dwelling women and their infants are usually discharged back to a hostel or other private accommodation whilst awaiting their return flight home. Some women reside on the hospital campus in the self-care unit if they have an infant admitted to the neonatal nursery.

Domiciliary care can be provided to women in Darwin, although the delivery of these services to remote dwelling women has been problematic and inconsistent in the past.

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<sup>1</sup> This situation, however, has improved for a number of women from selected communities who give birth at the regional hospital, since the Midwifery Group Practice which is described below, was established in 2009.

The DoH established the Darwin Midwifery Group Practice (MGP) in August 2009. This was partly in response to the findings in the *1+1* study and the findings reported in Chapters 4 and 5 of this thesis, as well recommendations in the 2007 NT Maternity Services Review and increased funding from the national government aimed at 'Closing the Gap' between the health outcomes for Aboriginal and non-Aboriginal Australians [43-45].

The establishment of the MGP represented a momentous change in service provision for remote dwelling Aboriginal women from seven selected communities, transferring to Darwin for maternity care, whereby they were able to receive continuity of midwifery care for the first time. The DoH aimed to improve the quality of care provision within a sustainable, culturally responsive, caseload model of maternity care. The service is community-based and integrated with both remote and tertiary services. The MGP provides continuity of care to approximately 190 women per annum when they come to Darwin for appointments antenatally, during labour and birth and postnatally until they return to their communities. Care is provided to women across all risk categories by known midwives and Aboriginal student midwives with support from medical and other multidisciplinary staff as required. An Aboriginal Senior Woman also works in the MGP and provides women with labour support in the hostel accommodation and in hospital [163].

#### **2.7.5 Paediatric care**

The hospital has a 23-bed paediatric ward and an 18-bed isolation ward, which cater for the 2397 paediatric inpatient episodes each year. The 18-cot Special Care Nursery and five-cot Neonatal Intensive Care Unit provide for more than 8000 episodes of care each year [158].

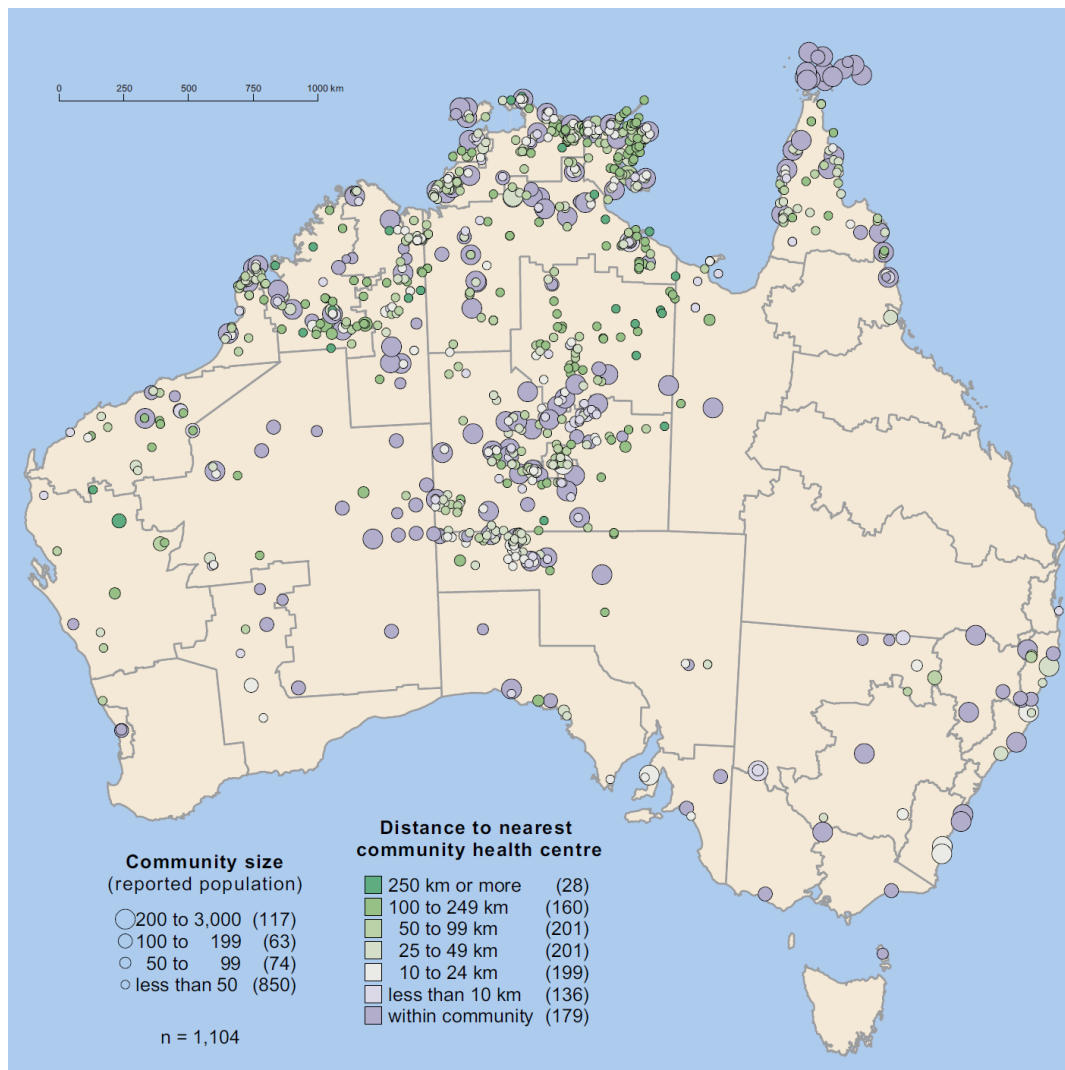
#### **2.7.6 Other hospitals in the Top End**

Other smaller regional hospitals (Katherine District Hospital and Gove District Hospital) also exist in the Top End but provide a more restricted range of MIH services. Private, fee-for-service maternity and paediatric care is also available at the Darwin Private Hospital. In excess of 90% of Aboriginal women from Darwin and surrounding remote communities give birth at the regional hospital [164], with very few Aboriginal women giving birth at Darwin Private Hospital.

### 2.7.7 Remote services

The physical proximity to health facilities and the availability of health staff determine access to health care. Across Australia, almost all remote Aboriginal communities with populations greater than 200 people have access to a HC within their community (see Figure 4). In the large communities where this does not occur, a HC was located within 25km, and typically within 10km [165].

In the Northern and Central parts of Australia where many smaller communities exist, the distance to the nearest HC can be more than 250km, presenting an enormous barrier to primary health care access for the community residents. In the NT, most remote communities, including larger communities, are located more than 250km from the nearest hospital [165].



## **Figure 4: Distance to nearest community health centres**

**Source:** Bailie R, Siciliano F, Dane G, et al. Atlas of Health Related Infrastructure in discrete Indigenous communities. Melbourne: Aboriginal Torres Strait Islander Commission (ATSIC); 2002: 50.

Remote health services are designed to provide high quality comprehensive primary health care services. This refers to 'essential health care based on practical, scientifically sound and socially acceptable methods and technologies which address the main health problems in the community through preventive, curative, rehabilitative and promotional services. It involves the treatment and prevention of disease and injury and the creation of the circumstances for personal and social wellbeing' [166].

### **2.7.8 Health facilities and health staff**

In remote Top End communities, health care is generally provided at a government, Aboriginal Community-controlled or joint national funded HC. Staff numbers within individual HCs differ depending on the size of the community, but usually include Remote Area Nurses (RAN) (of whom one may also act as the HC manager), midwives and CHNs and Aboriginal Health Workers (AHWs). Health centre services are provided free of charge.

Some larger RHCs have resident doctors (District Medical Officers, or DMOs) whilst others have fly-in-fly-out doctors who visit on a weekly or monthly basis. Remote community health services are less likely than those in urban or regional areas to have permanent onsite doctors or inpatient beds. High workloads are typical given the complex health needs of the population and the enormous burden of disease. More individual problems are addressed per consultation in Aboriginal health services than experienced in general practice services across Australia [145, 167].

Antenatal and PNC, and on occasion for unplanned birthing care, is usually provided by RANs (who may have midwifery qualifications), medical staff and sometimes AHWs, although this is community-dependent.

As there are few midwifery-specific positions, midwives often have to split their time providing acute remote nursing care as well as midwifery. Communities without midwives rely on support from visiting outreach midwives based at the regional centre.



Visiting specialists support community-based staff, although these visits are reportedly inconsistent across NT communities following the resignation of the outreach obstetrician and gynaecologist [7]. A visiting obstetric and gynaecology service has been provided to many remote communities by 'Specialist Outreach Services' since 1997 [98]. The visiting roster includes obstetricians from the regional hospital and two obstetricians who work in private practice along with an obstetric registrar and women's health nurse or midwife. Outreach midwives often undertake separate and more frequent visits to the communities.

Designated pediatricians and CHNs from the regional centre also provide a visiting service. The role of the CHN is to provide a well child service. In many communities across the NT there is no resident midwife or qualified CHN. The outreach midwives and CHNs often provide clinical care for women and their children in these communities, as well as support and education for resident staff. Outreach staff also provide supportive supervision to staff in communities that have resident midwifery and child health staff, although visits are not as frequent. Medical staff provide follow up for previously hospitalised patients or those with chronic medical issues and review patients on referral from HC staff.

### **2.7.9 Remote workforce issues**

Remote Area Nurses form the largest professional body of health care providers within remote health services. The mean age of a RAN in Australia is 44 years old, with 40% of RANs aged over 50 years [157].

There is a high turnover of nurses and midwives employed in remote NT communities, with an average turnover rate of 57% per year [168]. This is coupled with an ongoing shortage of staff and those with midwifery and child health qualifications have declined from 65% and 18% respectively in 1995 to 29% and 11% in 2008 [169]. Globally, the MIH workforces face a critical shortage of skilled maternity care providers, with an additional 700,000 midwives needed to provide care [170]. The long term workforce shortages experience in the NT health system reflect this worldwide situation. To combat the workforce shortages in remote health services, there has been an increase in the number of RANs employed on short-term, agency contracts or 'fly-in-fly-out' contracts, however numerous positions still remain vacant [157].

Limited career pathways for RANs, high workloads, long working hours (47.6 mean hours worked per week [171] compared with 38.6 for the average full-time employed Australian [172]) in addition to work-based violence and stressful work environments [173] contribute to RANs leaving remote practice. On average, nurses lose 2.8 hours of their work productivity each month due to physical or mental health issues [171].

The remote medical workforce also face critical shortages with a maldistribution of doctors working in capital cities, resulting in an urban oversupply of more than 4000 and an undersupply of around 500 in rural and remote areas. The shortage of procedural general practitioners and those with obstetric skills is also predicted to worsen over time [174].

### **2.7.10 Child health services**

Health care for children is described as ‘core business’ for remote health services [175]. Most AHWs and RANs do not have child health qualifications however; they provide the majority of acute and primary health care delivered to Aboriginal children, with medical staff consulting on referral. Common primary health care services include immunisations, child health assessments (with a particular focus on ear and oral health) and growth surveillance through the ‘Growth Assessment and Action (GAA) Program’. The GAA program was developed in the NT to improve the growth and nutritional outcomes of children from birth to age five. It involved regular growth monitoring and early intervention if growth faltering was detected, as well as health promotion around nutrition. The GAA program had three main objectives:

- Timely and accurate growth and anaemia monitoring of children
- Appropriate and timely intervention of growth faltering
- Reporting nutritional/growth status, including anemia prevalence at community, district and territory level [175]

The Healthy Under Five Kids (HU5K) Program was introduced in 2009 and absorbed the GAA program. The HU5K program also extended to include a number of new evidence-based, age-specific health and developmental checks in conjunction with the standard immunisation schedule and growth monitoring. The child health checks are an

important part of the program designed to enable prevention, early detection and management of common conditions and to facilitate timely referral for more severe or chronic conditions [175]. There is a self-directed educational training package that accompanies the HU5K program, which is unlike previous models of child health programs in the NT.

### **2.7.11 Treatment guidelines for maternal and infant health care in remote settings**

The Women's Business Manual (WBM) is the standard treatment manual endorsed by the DHF for women's health care in rural and remote communities in the NT. The manual provides guidelines and protocols to standardise practice in the areas of obstetrics, gynaecology, well women's screening, menopause, infertility and contraception [176].

The Council of Remote Practitioners Association (CARPA) Standard Treatment Manual is the main clinical manual used for the management of child health care. It provides a population approach to primary health care and management guidelines and protocols for preventive and curative child health care as well as chronic diseases, emergencies, mental health and drug problems, sexual health and other issues such as skin conditions, eye and dental health, adult health checks and brief interventions [176].

These two manuals are designed to be used by all health care providers working in rural and remote health settings in the NT, but RAN and AHW are 'obliged to adhere to their content, and are indemnified for their practice when providing treatment in accordance to the protocol for a given condition' [176]. Medical officers are also expected to adhere to the manual protocols but can also use their clinical judgement to decide an alternative treatment path [176].

Other resources used by remote staff to guide their clinical practice include the Remote Health ATLAS™, which provides governance and information about the processes and standards relevant to remote area practice and Best Practice Communiqués. These Communiqué are bulletins developed and distributed by the DoH and the Best Practice Group. They provide summaries of discussions and subsequent outcomes about a topic that has been addressed by the Best Practice Group. The Group regularly reviews

current practice and standards and decides upon 'Best Practice' to be implemented across NT remote health care [177].

### **2.7.12 Aeromedical services**

At the time of this study, emergency medical retrieval and evacuation from a remote community to a hospital was organised by medical staff through the Aerial Medical Service or 'Air Med' service, a government-funded 24-hour emergency service. Care Flight now provides this service.

Pregnant women who required evacuation for preterm labour, labour at term or other pregnancy complications comprised 21% of all urgent medical evacuations in 1997, the most recent data available [178].

## **2.8 Health Service Use**

In Australia, the use of mainstream primary health services by Aboriginal people is thought to be limited or prevented by multiple barriers previously outlined in Chapter 1. Little evidence exists however, about the actual patterns of MIH health care use in the remote dwelling populations. Whilst the barriers faced by Aboriginal people to accessing care are well described, no studies were identified that investigated the barriers experienced by clinicians who provide services to remote dwelling Aboriginal mothers and infants.

Improving health outcomes among remote dwelling Aboriginal mothers and infants is largely dependent upon improving the social determinants of health [179]; however health services can also contribute through the provision of timely and effective maternity care [180].

Maternity services delivered by a skilled birth attendant (defined by the WHO as 'an accredited health professional – such as a midwife, doctor or nurse – who has been educated and trained to proficiency in the skills needed to manage normal (uncomplicated) pregnancies, childbirth and the immediate PN period, and in the identification, management and referral of complications in women and newborns' [181, p1] during pregnancy, birth and the postpartum period can reduce maternal and

neonatal mortality and morbidity [182]. This is particularly true in areas where women's health status is poor [183].

### **2.8.1 Determinants of health service use**

The determinants of maternal health service use vary across cultures and are dependent upon individual and household factors, such as economic status, maternal age, level of formal education and place of residence, although many studies have not found consistent patterns of relationships between service use and these individual predictors [184]. Several international studies have described the influence of the consumer's perceived quality of maternal health services and subsequent utilisation. Women with obstetric complications in Ghana are reported to use emergency obstetric services if they feel these are of high quality [185] and in Mauritania, improvements in quality of health services led to higher use and willingness to pay for services [186]. Dissatisfaction and poor experiences with the service quality can lead to women seeking other alternatives for care or avoiding birthing services altogether. In Nigeria, women were prepared to use less well equipped and staffed community -based birthing services as opposed to giving birth in the hospital obstetric unit [187]. Similarly, in Australia some remote dwelling Aboriginal women only attend their local HC for the first time during labour, having had no ANC, so as to avoid being transferred out of their home communities to a hospital for birth [159].

Use of infant health services by Indigenous mothers across Australia has been associated with maternal marital status, age and educational attainment [188]. The most significant predictors of health service use in this population were financial status and distance from health services [188].

### **2.8.2 Maternal health service use in the Northern Territory**

#### **2.8.2.1 Pregnancy**

In Australia, ANC has been provided over many decades without rigorous scientific evaluation and little change in practice. The most commonly followed schedule of ANC is monthly visits up until 28 weeks of pregnancy, fortnightly visits until 36 weeks then weekly visits until birth. Wallace and Oats [189] identified that the frequency of visits could be safely reduced for women with low-risk pregnancies. Further international

research has shown that women with low-risk pregnancies who attend for fewer scheduled visits had the same maternal and perinatal outcomes as those who attended standard care and could reduce costs [190-191]. Reducing the number of visits from the traditional schedule was also found to be largely acceptable by clinicians and consumers [190-191] and provides more time to be dedicated at each visit for health promotion and education and addressing important social and parenting issues [192].

The Australian government in conjunction with the states and territory governments is currently developing national evidence-based antenatal guidelines. This is considered to be a priority area for maternity services as outlined in the 2010 National Maternity Services Plan [193].

Timely and highly quality preconception and ANC is the best preventive care for pregnant women to reduce maternal and perinatal mortality and morbidity [194]. The first ANC visit should ideally occur in the first trimester, as this is when early stage morbidity and mortality risk factors – particularly alcohol and smoking use and poor nutrition can – be best identified and addressed [195].

There is much literature describing different maternal health services for Australian Aboriginal women, often reported in the context of a program evaluation. Service use is frequently reported in urban and rural services [197-210] and predominantly focuses on the AN period. Fewer studies have been identified that address maternal health service use by remote dwelling Aboriginal women [98, 114, 159, 205, 211-212]. There is a scarcity of studies reporting maternal hospital admissions during the AN period [98,198] and infant admissions to the neonatal nursery [198].

Aboriginal women commence ANC later in pregnancy and attend for fewer visits compared with non-Indigenous women [98, 211, 213]. Most (78%) non-Indigenous Australian women attend for ANC in the first trimester whereas Rumbold et al. [211] identified only 34–49% of Aboriginal women in selected remote communities in the Top End, Central Australia, small regional towns in NSW and Western Australia presented for their first visit in the first trimester, with a mean gestational age of 16 weeks.

In Queensland, South Australia and the NT, more than 90% of women attend five or more AN visits compared with around 73% of Aboriginal women [99]. Inadequate ANC

(defined as three or fewer AN visits and a first visit occurring at 24 weeks gestation or later) has been associated with low birth weight among Australian Indigenous women from Townsville [196].

Much anecdotal evidence also exists among clinicians in the NT to suggest that Aboriginal women and their infants do not regularly attend health services and this is then one of the reasons for their poor health outcomes; however there is an absence of published data from the relevant communities and hospital to confirm this.

### **2.8.2.2 Birth**

The vast majority of births in Australia occur in a hospital facility. In 2010, approximately 64.7% of women who gave birth in hospital were admitted to the public system, with the remainder birthing in private, fee-paying hospitals (33.9%) and a small minority of women choosing to birth at home (0.3%) [213].

Women living in rural and remote areas face greater inequalities in maternity service access resulting from the dramatic decline in the number of rural maternity services as well as qualified obstetricians, general practitioners (GPs) and midwives working in these settings [214]. In the NT, the majority of Aboriginal women (95.2%) give birth in hospital, as do non-Aboriginal women (98.8%). However, of the non-Aboriginal mothers who give birth outside of hospital, the majority of these births are planned, well supported home births. Whilst for Aboriginal women, most of the out-of-hospital births occur at the RHC [215] often in circumstances that had not been arranged prior to labour commencing or supported by health centre staff [159].

### **2.8.2.3 Birthing in remote communities**

In the late 1990s Kildea [114] identified up to 27% of pregnant Aboriginal women from Top End communities gave birth in remote communities. In 2008, Ireland [159] undertook a study in one of the largest remote Top End communities, to investigate the experiences of Aboriginal women who do not participate in the standard model of maternity care. Ireland identified around 10% of women from a large remote Aboriginal community gave birth outside of the hospital system, predominantly in a RHC. Both Kildea and Ireland identified that a number of the women birth in these remote communities in unplanned circumstances (e.g. preterm birth or precipitous labour).

Other women consciously chose to give birth in their home community, to avoid being transferred to a hospital and away from their families [114, 159]. These women may have some ANC at a RHC or not engage with the health system at all during their pregnancy and only present for the first time when they are in labour. A number of women choose to remain in the community for birth because of prior negative experiences with the hospital system [159].

#### **2.8.2.4 International experience of remote birthing**

Many remote health services currently lack the funding, infrastructure and staffing to safely support birthing in the community as a standard option for women, despite this being a key request by remote dwelling women for a number of decades [7,114,154]. However, the experience of Indigenous populations in other countries, who have similar demographics and health outcomes, suggests that these issues can be resolved. The provision of innovative, culturally acceptable and safe birthing services for Indigenous women living in remote regions of North America and Canada has been provided for many years with beneficial outcomes for mothers and babies [216-219]. The use of remote maternal health care services by Inuit women, which incorporate continuity of care and birthing in home communities, has resulted in improvements in AN visit attendance, rates of labour intervention and birth outcomes when comparing results across other regions [216-217].

A cohort study investigating health outcomes for Navajo Indian women who used birthing services in remote areas of North America that did not have onsite surgical facilities for caesarean sections, supported the provision of remote birthing services [218]. No adverse outcomes were experienced by any mother or baby as a result of utilising these birthing services and the overall health outcomes were deemed equivalent or better than those of the rest of the population.

These models of care, whereby women and infants are cared for locally with continuity of midwifery care in addition to having social networks and family actively involved, have not only demonstrated an improvement in MIH outcomes but are claimed to contribute to improving community functioning and social cohesion [217, 219].



### 2.8.2.5 Postpartum

Among the maternity service provided by individual states and territories in Australia, there is particularly wide variation in the level of postnatal services that are provided to families. During the early postpartum period, most mothers and infants in Australia move from acute-based maternity services to community-based services. These include general medical practitioner services or free, universal services provided by child and family health nurses, from birth to age five [220].

The manner of this transition differs across the country but usually occurs in the first two weeks postpartum though may occur as late as two months [220]. During this period, where women move from one service to another, it is critical that they are connected with services to support their transition into the parenting process [220].

Universal home visiting services are provided by child and family health nurses in the majority of urban and regional areas of Australia. Access to these services and indeed qualified child health staff are more limited in rural and remote areas [221]. Widdup et al. [222] recently identified that Aboriginal families and families with vulnerabilities (such as young age of mother, low educational attainment or a single mother) who lived in urban areas of New South Wales were also considerably less likely to receive a home visit by a child and family health nurse within the first two weeks following the birth of their infant, compared with non-Aboriginal families (43% vs. 58%). Issues related to the referral process between the hospital and community health service, mislaid paperwork and lack of contact details for the families were some of the reasons identified by the authors for the families not receiving a home visit. These home visits are designed to provide families with their first PN visit in their own environment, introduce and facilitate early access to child and family support services and, importantly, 'identify and engage vulnerable and disadvantaged families' [222, p28]. Similarly Homer et al. [220] also identified the lack of collaboration and coordination between service providers and services themselves in transition of PNC from acute to community-based services.

There is currently limited population data about postpartum health service use by Australian women and an absence of evidence detailing PN health outcomes of remote dwelling Aboriginal women and patterns of primary and referral level health service use.

### 2.8.2.6 Infant health services

Australian infants have a higher percentage of visits to a medical practitioner in their first year than at any other time in their life, averaging 4.2 visits by six months of age [223]. Contact with urban-based MCH nursing services is also high. Goldfeld et al. [223] identified 97.6% of families accessed this service, with a mean of 14.3 visits in the first year of an infant's life.

Recent studies describing primary level health service use by remote dwelling Aboriginal infants are limited [151, 224-226]. Clucas et al. [226] undertook a retrospective review of remote clinic records to investigate use of remote primary health clinics by children under five in East Arnhem communities. Only data on presentations for infectious reasons were reported and those related to routine, preventive care were excluded. Infants were identified as frequent users of primary health services, presenting on average twice per month, mostly for upper respiratory tract and skin infections. High rates of primary health service utilisation have also been identified among infants of middle income, suburban Victorian families; however the bulk of the visits were unrelated to acute illness and were predominantly for preventive health care provided by a MCH nurse [223].

In contrast, data drawn from a nationally-representative, large retrospective cohort study investigating the differences between health service utilisation in Indigenous and non-Indigenous infants, identified that Indigenous infants had a significantly lower level of primary and referral level health service use than that of non-Indigenous infants (2.5 vs. 3.1 visits) [188]. Regarding specific health services, Indigenous families were also much less likely than non-Indigenous families to use a MCH centre or help line (32.7% vs. 58.4%); MCH nurse visits (48.7% vs. 68.0%); a general practitioner (67.7% vs. 82.5%) and paediatrician (25.0% vs. 39.1%) but were admitted to hospital more frequently (17.3% vs. 9.9%) and used hospital outpatient services more frequently (16.3% vs. 9.7%) [188]. Similarly, Widdup identified lower numbers of child and family health service visits by Aboriginal infants in urban NSW community HCs compared with non-Aboriginal infants from birth to 15 months of age (4.6 vs. 5.2) [222].

There is a scarcity of current data about use of referral level health services by remote dwelling Aboriginal infants. Many studies on hospital use describe admissions by

Aboriginal children aged less than five years [227] and often restrict their data collection to specific disease types, such as diarrhoeal or respiratory infection and aggregate area of residence. One study reported patterns of hospital admission by children from remote NT communities [228]; however data were from the mid-1970s–80s.

Ou et al. [188] identified that remote dwelling infants are twice as likely to be admitted to hospital than their non-Indigenous counterparts but the reason for admission was not specified. Studies in the NT and Queensland show higher rates and longer lengths of admissions among young Aboriginal children, particularly when admissions were related to infectious disease and malnutrition [229].

## **2.9 Quality of Health Service Delivery**

### **2.9.1 Quality of care concept**

Whilst access to and use of health services is a critical factor for good health outcomes, it does not necessarily ensure quality of health service delivery [230]. Health services that provide substandard or poor quality care contribute to poor maternal and infant outcomes [231].

One of the most prominent models of quality of care in health service delivery was developed by Donabedian [232]. He proposes quality of care can be measured on the basis of:

- **Structure:** Characteristics of the health facility, such as physical structure, equipment, health care provider qualifications, organisation and structure, administrative structure and fiscal health
- **Process:** The components of the interaction between the health care provider and the consumer/patient, such as diagnosis and treatment, consultation, referral, coordination and continuity of care
- **Outcome:** The consumer's health status / health outcomes [232]

Quality of health services can be defined from the perspective of the patient or the population level. The patient perspective defines quality of health services as 'whether individuals can access the health structure and processes of care which they need and

whether the care they receive is effective' [233, p1614]. Alternatively the population perspective defines this as 'the ability to access effective care on an efficient and equitable basis for the optimisation of health benefit/wellbeing for the whole population' [233, 1617].

Bergstrom outlines the following criteria that should be fulfilled to provide high quality maternity care [234]:

- Be based on technical competence of health care providers with clear guidelines for treatment
- Involve mother in decision making and see her as a partner in health care
- Strive for continuity of care and follow up
- Be available as close as possible to where the mother lives and be at the lowest level facility that can provide the services safely and effectively
- Be equipped with essential supplies
- Provide counseling and information for mothers regarding their health and health needs
- Be responsive to cultural and social norms and thereby be acceptable to potential users regarding preferences for privacy and confidentiality
- Give comprehensive care and linkage to other reproductive health services
- Give social and economic support to health care providers to enable them to provide an optimal service
- Be staffed by workers providing respectful and nonjudgmental care, responsive to women's needs.

### **2.9.2 Quality of health service delivery to remote dwelling Aboriginal mothers and infants**

Previous research provides limited data on the quality of maternity services for remote dwelling Aboriginal women [98, 102, 211] and focuses predominantly on ANC.

These studies typically draw their data from one source; either the hospital or the RHC medical record [98,102, 211], whereas it is known that Aboriginal women from remote areas usually access pregnancy services at both health sites thus potentially underestimating the results if relying on only one data source.

International research has shown that inadequate ANC, which includes failure by health staff to provide routine screening or treatment for known risk factors and complications, contributes to potentially avoidable, poor maternal and infant outcomes, including death [235-236].

Studies that have included Aboriginal women from remote NT communities have reported considerable deficiencies in the delivery of best practice-based guidelines for ANC and PNC. Documentation of routine laboratory investigations at the first AN visit was between 63–82% for all women and routine health checks (including blood pressure and urinalysis) ranged from 10–45% for women who presented before the first trimester, increasing to 72–81% in the third trimester [98, 211].

Poor follow up and treatment of abnormal clinical findings detected antenatally, such as urinary tract infections and anaemia, were consistently highlighted across a number of studies [98, 102, 211]. Documented treatment varied widely across health services, for example, antibiotic treatment for urinary tract infections ranged from 32% [102] to 43–49% [98] to 61% [211].

Low rates of screening for congenital abnormalities [98, 211], smoking cessation advice provided to women identified as smokers during pregnancy (46% [211] to 80% [98]) and postpartum rubella vaccination among women identified as lacking immunity to rubella (31% [211] to 75% [98]) were also major issues identified in the Australian studies.

Despite the disproportionately high burden of illness and disease endured by young, remote dwelling Aboriginal children, there is a lack of data investigating the quality of health services provided to this population. A small number of studies included remote dwelling Aboriginal children under five; however data related specifically to infants was scarce [151, 225]. These studies focused predominantly on quality of care provided at the primary HC [151, 225] and neither examined factors that affect the delivery of services. Understanding these factors would assist clinicians, managers and health planners to develop tailored strategies for quality improvement. Quality was generally measured by adherence to local best practice guidelines. No studies were identified that examined quality of care provided to remote dwelling infants in hospital.

Anaemia, growth faltering, ear disease and respiratory infections are highly prevalent among infants [151, 225], which concurs with other studies describing common illness in Aboriginal infants [226, 237-238]. Bailie et al. identified that schedule-based clinical examinations – such as growth and anaemia monitoring, development, hearing, vision, heart and ear checks – were undertaken in 48–97% of children under 5 [151]. However, there were significant deficiencies in the delivery of follow-up care for abnormal findings, particularly for anaemia, growth faltering or failure to thrive and chronic ear disease or respiratory tract infection [151]. Documentation of brief interventions or clinician advice on health risks and behaviours were poor. Despite most infants being born in a hospital and experiencing a high rate of hospital admissions early in life, there were no known studies that investigated the quality of service delivery for remote dwelling Aboriginal mothers or their infants during the transfer of care from their remote community to hospital or *vice versa*.

## **2.10 What Constitutes Effective Service Delivery for Remote Dwelling Aboriginal Mothers and Infants?**

Numerous maternal health programs and services have been established to provide culturally responsive health care to Aboriginal women and their infants and address the problems of mainstream service design and delivery [99, 239]. Outcomes of the individual services have been variable but most notably, improvements occurred in ANC attendance and care [205, 240-247], satisfaction and perceived benefit of services by consumers and service providers [198, 206, 212, 244-246], increased birth weights in babies born to Aboriginal mothers [196, 212, 242, 243, 246, 247, 248], increased breastfeeding rates, immunisation coverage [241, 245, 248-249] and use of early childhood services [249]; there were also decreases in the proportion of women smoking [198, 203-204, 240], perinatal mortality [205, 240, 248], low birth weight [248, 242-243] and preterm birth [196, 247].

These services have predominantly been based in urban or regional settings and focus on the provision of ANC and PNC – using a primary health care approach – but seldom include birthing services or evidence-based redesign of remote health services. Further, restricted funding has curtailed some of these services to being of limited scope. Transferability of these programs and services to other communities is hampered by

their varying degrees of success, limited evaluation and the difficulties of interpretation of data sets based upon small communities [250].

Congress Alukura in Alice Springs was the only Aboriginal community-controlled, primary health care model of a comprehensive maternity service that has been established to incorporate and recognise Aboriginal law, language and culture, especially as they relate to pregnancy and childbirth. However, Alukura has never been able to regularly provide onsite birthing services and the scope of birthing services have been further reduced over the years due to staffing and funding issues [212].

Multiple factors have been identified as ‘underpinning’ successful models of MIH care that are known to be effective in improving MIH outcomes for Aboriginal families. Despite a lack of robust evidence, Herceg [239] indicated a number of essential factors for effective services, which include:

- providing services that are Aboriginal-controlled or community-based
- providing home visiting, outreach activities and continuity of care, and integrate with other services, such as a hospital or hospital liaison
- providing services in a designated location for women and their children
- providing services in an environment that is welcoming and safe
- providing flexible appointment times and service delivery
- focusing on communication, relationship building and development of trust
- respecting Aboriginal people and their culture
- respecting family involvement in health issues and child care
- having an appropriately trained workforce
- valuing Aboriginal staff and female staff
- providing transport
- providing childcare or playgroups
- Aboriginal and non-Indigenous workers providing care in partnership and involving Aboriginal people in a meaningful way in services and programs that impact upon their own health.

Cultural competency of health service providers and inclusion of AHWs can improve the quality of patient services, such as improving attendance of women for ANC and women’s satisfaction with services [197,199, 205, 251-253]. Kruske et al [254]

reinforce the crucial need for greater understanding of Aboriginal child rearing practices and parenting by health care providers so any differences in parenting behaviours and values are incorporated into health messages. Non-Aboriginal clinicians working in RHCs with Aboriginal families were identified to 'provide health advice and information from their own perspective' [254, p784] with 'expectations of child development expectations that support middle class non-Aboriginal beliefs at the expense of Aboriginal knowledge' [254, p785]. Kruske et al argue that current remote child health services fail to incorporate an understanding of Aboriginal parenting styles and Aboriginal knowledge systems, which contributes to the ongoing failure of the health services to improve health outcomes for young Aboriginal children.

Continuity of care as well as effective coordination of services and collaboration within services have been repeatedly highlighted in the literature as critical factors to improve quality, safety and efficiency of service delivery for Indigenous Australians [255].

### **2.10.1 Continuity of care**

Continuity of care in maternity services enables women to 'develop a relationship with the same caregiver(s) throughout pregnancy, birth and the PN period' [256, p2]. Hodnett [256 p2] defined continuity of care as:

1. 'a stated commitment to a shared philosophy of care
2. a strict adherence to a common protocol for care during pregnancy and/or childbirth
3. a system whereby those who are discharged from hospital are routinely referred to community services, or
4. the actual provision of care by the same caregiver or small group of caregivers throughout pregnancy, during labour and birth, and in the PN period'.

The most common models of continuity of care provided in Australia are shared care between a general practitioner/doctor in a community health service and the hospital, midwifery group practices and team midwifery.

The concept of 'continuity of carer' refers to a woman having the same health care provider throughout her pregnancy, labour, birth and postpartum. Women typically access this type of care through a caseload midwifery practice model, a private



midwifery practice or in private obstetrics [154]; although in private obstetrics other midwives are usually involved in the provision of labour and PNC as well as the private obstetrician. Strong evidence demonstrates that continuity of midwifery carer during pregnancy, birth and postpartum leads to numerous positive outcomes for mothers and infants when compared with traditional models of care [256-259] and responds to the individual need, preferences and expectations of women [154]. Outcomes include:

- reduced interventions during labour, especially pharmacological pain relief, augmentation and use of electronic fetal monitoring (cardiotocography, or CTG) [256]
- reduction in caesarean sections [258-261]
- increased maternal satisfaction with care and pregnancy and birth experiences [262]
- improved readiness for birth and parenting [256] and increased participation in decision making [263]
- improved self-confidence and self-esteem in the early postpartum period [264]
- reduction in neonatal resuscitation [256]
- reduced health costs [154].

### **2.10.2 Collaboration**

Several maternity service reviews confirmed the importance for maternity services to 'work within collaborative and consultative frameworks in order to achieve positive health outcomes and a closer matching of services to women's needs, preferences and expectations' [265, p6]. The Primary Maternity Services in Australia framework [266], released in 2008, stresses the need for all midwives, obstetricians and general practitioners to value the different contributions made by the distinct professions that provide maternal health care and to ensure collaboration between clinicians exists at all levels of the health system in order for safe services to be provided. Collaboration extends beyond individual clinicians working together; it also encompasses working within and across different health services and established networks to enable the timely and appropriate transfer of care when needed. These collaborative networks within a health system are deemed as 'critical for enabling access to safe effective quality services' [266, p7].

### **2.10.3 Coordination**

Effective service coordination improves the quality of services and delivers benefits to service providers [267-269]. Service delivery coordination is ‘underpinned by a common purpose: to improve the connections between services or between people and services in order to improve outcomes for individuals, families, communities and societies’ [255 p11].

The complexity of the health system available to Indigenous people in Australia can result in fragmentation of services, miscommunication between health care providers and missed opportunities for care delivery to patients [270].

Service delivery coordination is especially important for remote dwelling populations as it has been identified that an individual service (such as a HCs) is unable to singlehandedly manage the various multifaceted issues faced by the service consumers, such as housing, transport, finances, family issues and health care [255]. Lawrence [270] successfully demonstrated through a small, inexpensive action research project how improved liaison and coordination between the NT health care system and remote dwelling Aboriginal cardiac patients led to improved patient care and considerably reduced service waiting times and health costs. There is little evidence however, both in Australia and internationally, to demonstrate whether improving service coordination actually leads to better health outcomes for service consumers [255].

### **2.10.4 Clinical governance**

An effective system of clinical governance is also an essential component of the quality and safety of health service delivery in Australia. Clinical governance is defined by The Australian Council on Healthcare Standards as:

‘...the system by which the governing body, managers, clinicians and staff share responsibility and accountability for the quality of care, continuously improving, minimising risks, and fostering an environment of excellence in care for consumers...’ [271 p3].

## **2.11 Summary**

Investigating the quality and use of maternal health care services for remote dwelling Aboriginal women and infants addresses a well identified need by government, health planners and researchers. There are however, large gaps in the evidence around patterns of health service use by mothers and infants. Despite a high burden of disease identified among mothers and infants, there is little data describing the quality of service delivery provided and the barriers that may be faced by clinicians when attempting to provide this care. Similarly there is little data identifying how health services are delivered to remote dwelling Aboriginal mothers and infants across the continuum of care and where quality of care is potentially compromised.

The following chapter provides an overview of the methodology and methods that were utilised for this study.

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# 3 METHODOLOGY

## 3.1 Introduction

This chapter summarises the research methods used in Chapter 4, a description of the patient journey across the NT health system and in the publications that comprise Chapter 5. Each of the publications includes its own description of the health services and contains a detailed methods section and will not be repeated here. This chapter, however, will provide additional detail on the remote community populations, study design and data collection procedures, research instruments, data analysis and the ethical considerations.

## 3.2 Setting

### 3.2.1 Study location

This study was conducted across three purposefully selected sites: Communities A and B and the regional referral hospital for both of these communities. Communities A and B are two of the largest remote Aboriginal communities located in the ‘Top End’ region of Australia’s NT. These communities are located approximately 500km from the regional centre, Darwin, where the hospital is located.

### 3.2.2 Remote community population

The high mobility of individuals within remote communities in the NT makes accurate population estimates difficult [1-2]. In the 2006 census, undertaken during the study period, Community A and its outstations had an estimated population of 2781 and Community B, 2222. There is a young age profile in both communities, with around half of all people aged less than 20 years and more than 12% aged 0–4 years. Ninety-three per cent of people in these communities identified as Indigenous [3-4].

Both communities have many outstations/homelands surrounding the community itself. These communities serve as a residence for hundreds of the people during the year and often people will move into the community itself during the wet season [3-4], which impacts upon the service population and workload for the HC.



### **3.2.3 The remote communities**

Most people in Communities A and B experience poverty and live in overcrowded and poorly maintained houses [5]. Road access from these communities to Darwin, the regional centre is only available during the dry season. There are twice daily flights to both communities on a commercial airplane.

Unemployment is high and local employment opportunities and industry is limited. In Community A, industry is based around art and craft and fishing tourism whilst in Community B, employment opportunities are often related to local council or government programs [6-7]. Access to adequate sanitation, water supply and building repairs are not the same as in larger regional centres [8]. Food supplies are delivered from Darwin via a boat several times a month, however the cost of fresh food items in 2006 was around 29% higher (ranging from 24–56%) in remote communities compared with Darwin [9]. This makes access to affordable, nutritious food very limited for most people who have among the lowest mean incomes in the country [11].

Tradition, culture and local languages are strong. Multiple clan groups and languages exist in each community and the majority of people speak local languages, with English often being their second or third language [3-4]. There are local councils, some shops and schools in both communities as well as a government-operated HC. Women and infants requiring hospitalisation are transferred to the regional hospital for this care.

### **3.3 Study Design**

A situational analysis methodology comprising mixed methods was used in this study. This methodology was originally established to investigate the availability and quality of family planning and reproductive health services in Kenya and has been implemented and validated in numerous countries [12-13].

The methodology is designed for use with a variety of research techniques to assess the functioning and quality of a health service and incorporates participatory processes to help define and solve health service issues.

The recommended methods for undertaking a health service situational analysis include medical chart audits, interviews with consumers and service providers and

observational studies using current validated assessment tools [12]. A mixed methods approach was clearly needed in this study to produce a more comprehensive, descriptive and accurate overview of the MIH service than what would be possible using a single method [14]. The use of multiple sources of data would also provide a source for cross-checking of results and to validate the study findings.

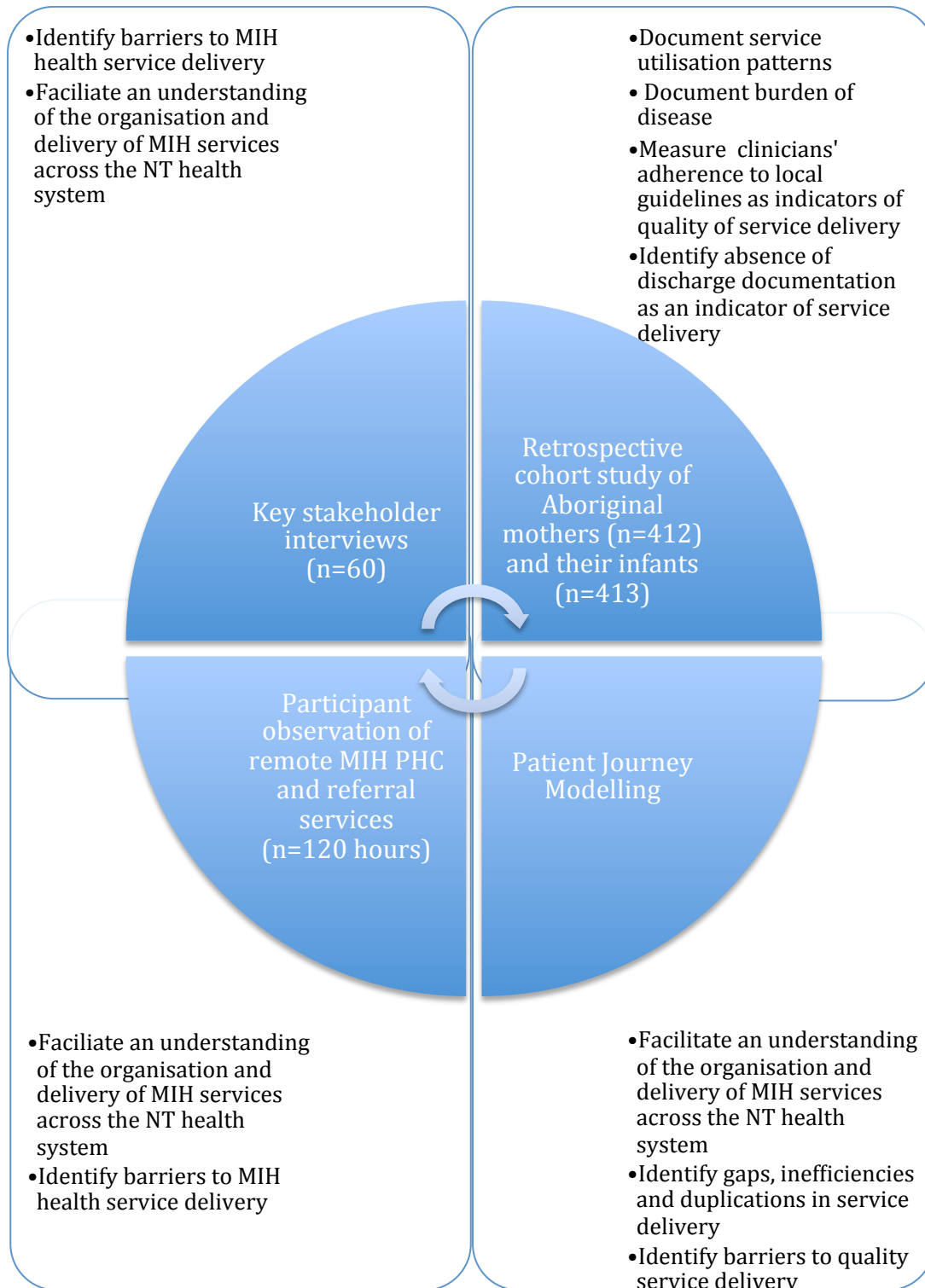
### **3.3.1 Continuum of Maternal and Infant Care (COMIC) assessment framework**

There is a well-recognised need for service integration and continuity of carer across maternal, newborn and child health services [15-17]. However there is a lack of available tools or frameworks available to evaluate quality and use of care delivered across this continuum. Many health system assessment frameworks and tools exist for the evaluation of single aspects of MIH services, i.e. access to emergency obstetric care [18], assessing competence of skilled maternity care providers [19], quality of referral care systems [20] and management of adverse events [21]. When this study was being designed there was a gap in the availability of a comprehensive framework that could be used to evaluate the quality and use of health services systematically across the continuum of care.

Given that the health system under investigation was large and complex – involving multiple transitions back and forth between remote primary health care services and hospital services – it was necessary to develop an independent framework for data collection that was relevant to the NT health system context and would capture maternal and infant data from the across the continuum of care. Drawing on the principles of situational analysis, the COMIC assessment framework, comprising four distinct but interdigitating components, was developed to facilitate comprehensive data collection and enable the objectives of the study to be achieved (see Figure 5).

The qualitative data collection in this study was also designed to be conceptually linked through Patient Journey Modelling (PJM) [22]. This is an innovative health care quality improvement technique that can be used to model the processes involved in a patient's journey through either a single health care service or through multiple health services [22] (e.g. from a the remote HC to a regional hospital and back to the remote HC for ongoing care). This information is then used to identify duplications and bottlenecks in

service delivery and system usage and improve the quality and safety of patient-centered care through service redesign.



**Figure 5: COMIC assessment framework: Methods and objectives**

## **3.4 Sample Selection**

### **3.4.1 Retrospective cohort study**

During the study design phase of this research it was determined that studying the combined birth cohort of the two communities was feasible and practical and would result in statistically and clinically significant measurable outcomes.

It is likely that a number of factors, independently and in combination, serve to affect the health outcomes of women and children. Many of these factors are known anecdotally (such as smoking, young maternal age or birth weight) but the prevalence of these factors and the degree of correlation between these factors and outcomes for mothers and children have not been studied in detail for Aboriginal populations in Top End communities. For some of these factors, studies conducted in Aboriginal populations in other parts of Australia [23-24] and in other populations from resource poor settings do exist [25-26].

An analysis of such multiple factors and their impact on outcomes would involve a multiple regression analysis and the sample size was determined on this basis. However, this analysis is yet to be undertaken and this doctoral study reports predominantly to descriptive statistics. This was due to the direction the study took (already of significant size) and the decision to conduct the analysis as the final data set of the overarching *1+1* study, which has taken five years to collect. It is anticipated that a multiple regression model will be developed as part of future research and this is discussed further in Chapter 6.

A justification for the sample size is still indicated and outlined below. The sample size calculation for multiple regression analysis may be based on either of two complementary approaches. The first approach makes assumptions about the null hypothesis – in this case the true prevalence of some given factor of interest – and the calculated sample size relates to the ability to accept or reject, within a specified level of power, the null hypothesis, i.e. that the factor as measured in the study does in fact reflect the true factor. This approach is often referred to as a power analysis (PA) approach. An alternate approach described by Kelley and Maxwell [27] depends on the assumed strength of correlation between the factors in the regression analysis and the

outcome of interest. This latter approach also has the advantage of allowing the researcher to predetermine the narrowness of the confidence intervals around the parameter of interest without requiring knowledge of its prevalence in advance. This approach is referred to as the Accuracy In Parameter Estimation (AIPE) approach. Thus a number of models may be developed, using differing assumptions about the strength of association (the correlation) between a factor of interest and outcome of interest, and about the correlation among a factor of interest and the other factors measured. These different assumptions provide various sample sizes without requiring prior estimation of the prevalence of that factor in the population. For example, and based on Kelley and Maxwell [27], for a regression model measuring five variables with an outcome of interest, and assuming that:

|            |   |      |  |
|------------|---|------|--|
| $p$        | = | 5    | number of predictor variables in full model          |
| $\alpha$   | = | 0.05 | alpha level for confidence interval                  |
| $w$        | = | 0.15 | confidence interval half-width                       |
| $R^2$      | = | 0.17 | R-squared for full model                             |
| $R^2_{xx}$ | = | 0.29 | R-squared for target predictor with other predictors |

The sample size required was calculated to be 228 (in this study this was 228 mother-infant pairs). This would allow confidence intervals to lie within  $2w$  ( $\pm 0.15$ ) 80% of the time. While  $R^2$  and  $R^2_{xx}$  are continuous variables, levels of strength of correlation (small, medium, large) have been conventionally described [28]. In the example above the values used correspond with a medium to large degree of correlation for the parameters  $R^2$  and  $R^2_{xx}$ .

Allowing for a wider confidence interval around any resulting point estimate by increasing the value of  $w$ , would have resulted in a smaller sample size. For example, substituting  $w=0.2$  in the above equation yields a sample size of 136 mother-infant pairs.

The effect of the number of measured predictor variables ( $p$ ) on sample size is more modest. For example, in the above equation leaving  $w=0.15$ , but reducing the number of measured predictor variables from 5 to 4, results in a sample size of 226. And further

reducing to  $p=3$ , equates to a sample size of 224. Alternatively, raising  $p$  to 6 results in a sample size of 230; when  $p=10$ , the sample size required is 238.

The anticipated birth cohort over a 12-month period for women from both the study communities combined was 114, based on previous data [29]. Substituting the relevant values into the Kelley and Maxwell [27] equation shows that a sample size of 104 would still allow for 10 parameters to be evaluated in a multiple regression analysis and result in an estimate with confidence intervals no wider than 0.25 around the resulting point estimate for the correlation parameter of interest in 80% of the time of hypothetical repetition of such a study.

An alternative option for a retrospective cohort study that aims to determine the prevalence of specific factors of interest but where this prevalence cannot be estimated because of a lack of pre-existing data is to use the PA approach, but to model calculations around an assumption of 50% prevalence [30]. A prevalence estimate of 50% is safest since it results in the greatest sample size. Reducing or increasing the point estimate from 50% results in symmetrically reduced sample size. Using this approach with a 95% confidence level and a precision of 0.2 ( $\pm 0.1$ ) about the point estimate requires a sample size of 96. This calculation is based upon only one factor of interest, and is likely to be underpowered for a regression analysis of several factors at once. Nevertheless, this example serves to illustrate that triangulating a sample size using a different method altogether from that of Kelley and Maxwell [27] results in a sample size of comparable magnitude.

As explained above, prevalence of a factor of interest may be used to more accurately determine the required sample size beyond the safest assumption of 50% prevalence. Using examples from data regarding Aboriginal women in the NT [31] demonstrates this point. For instance, medical complications occur in 46% of Aboriginal women in the NT, so a sample size of 96 (suitable for a prevalence of 0.5) is appropriate. The prevalence of maternal age younger than 20 years is about 30%. Based upon this prevalence, a sample size that will determine with a 95% confidence level and a precision of 0.2 ( $\pm 0.1$ ) about this point estimate of 0.3 will be 81. For anaemia, with a prevalence of 19%, the sample size would be 61. For low birth weight with a prevalence of about 13%, the required sample size is 49. Thus, using the PA approach [30] and the

AIPE approach [28], a sample size of about 100 women-infant pairs is appropriate. This number corresponds well to the combined annual birth cohort of the two communities.

### **3.4.2 Pilot process**

Initially, it was difficult to anticipate the completeness of medical record data and access to the number of records available for analysis. A pilot data collection phase revealed that many data variables were incomplete. It was therefore decided by the *1+1* research team that it would be beneficial to extend the data collection period beyond the initial one year that the sample size calculation was based on, to a 3 year period (2004–2006).

### **3.4.3 Interviews**

It was not possible or necessary to calculate an exact sample size for the qualitative arm of the study. Sampling was therefore purposive, with a diverse range of key health care professionals and other service providers selected for participation in individual interviews based on their 'role' in the MIH care system. Snowball sampling was also used following the initial round of interviews to determine other potential participants who were not initially identified for inclusion in the research. Two co-researchers on the *1+1* study who had extensive work experience in all the study sites and myself worked together to develop a list of key stakeholders (interview participants). It was initially estimated that approximately 40–50 participants would be needed to capture a wide range of views and professional roles; however, 60 interviews were conducted, as this was the point where saturation of the data appeared to be complete.

Qualitative and quantitative data were used to inform the description of the patient journey through the NT health system outlined in Chapter 4. The papers within Chapter 5 drew upon the data from the interviews, retrospective cohort study and observations within the MIH services. The study designs and methods of data collection used in Chapter 5 are summarised in Table 2.

**Table 2: Summary of study designs and methods of data collection**

| <b>Paper</b> | <b>Contents of paper</b>   | <b>Study design and population sample</b>   | <b>Data collection methods</b>   |
|--------------|--|---|--|
| <b>1</b>     | Disease burden and patterns of health service use during pregnancy, birth and six months postpartum.         | Retrospective cohort: All Aboriginal women who gave birth 2004–2006, at hospital, remote community, hostel, in transit to hospital (n=412). | Hospital and HC medical record audit.                                  |
| <b>2</b>     | Quality of ANC measured by staff adherence to local clinical guidelines.                                     | Retrospective cohort: All Aboriginal women who gave birth 2004–2006, at hospital, remote community, hostel, in transit to hospital (n=412). | Hospital and HC record audit.  |
|              | Barriers to ANC delivery at hospital and HCs   | Snowball and purposive sample (n=28 interviews)   | Semi-structured interviews   |
| <b>3</b>     | Transition of care in the PN period from hospital to RHC.  | Retrospective cohort study: all Aboriginal women who gave birth 2004–2006 at regional hospital (n=371).                                     | Hospital and HC medical record audit.                                  |
|              | Factors affecting the quality of the transition of care and the related consequence for mothers and infants. | Snowball and purposive sample (n=60 interviews). 80 hours of observations of PN hospital services and remote maternity services.            | Semi-structured interviews. Structured observations (hospital and HC). |
| <b>4</b>     | Patterns of infant hospital and HC use.  | Retrospective cohort study: all Aboriginal infants born 2004–2006 (n=413).  | Hospital and HC medical record audit.                                  |
| <b>5</b>     | Quality of remote infant health service delivery, using anaemia and growth faltering as indicators.          | Retrospective cohort study: all Aboriginal infants born 2004–2006 who had a RHC record (n=398).   | HC medical record audit.   |
|              | Barriers to infant health service delivery at the HCs.   | Snowball and purposive sample (n=24 interviews).  | Semi-structured interviews.  |



## **3.5 Data Collection Procedures**

### **3.5.1 Interviews and observations**

Data collection occurred concurrently during 2008. Sixty semi-structured interviews were conducted with key health, management and administrative staff employed in the HCs (n=30), the regional hospital maternity, neonatal and paediatric units (n=18) and other staff providing clinical, administrative or logistical support for remote dwelling women during pregnancy, around the time of birth and during the first year of their infant's life (n=12). Interviews were designed to capture staff views on the organisation, quality and barriers to service delivery as well as strategies for improvement. The interviews were designed to take no longer than 30 minutes, specifically to reduce the burden on the participant, as it was anticipated that the interviews would take place during paid work time. The HC managers had approved staff to utilise work time to participate in this research prior to the interviews being undertaken although most interview participants preferred to meet outside of working hours, either at their home or the local university campus. All interview participants were offered a copy of their interview transcript, copies of the publications arising from the study and newsletter updates from the *1+1* study. None of the participants who accepted a copy of their interview transcript requested any changes to the text.

One hundred and twenty hours of participant observation was undertaken to collect data on the service organisation and delivery. Observations occurred within the hospital AN clinics, birth suite and AN and PN units and at the HC in the women's health rooms (80 hours) and child health services (40 hours). Health centre and hospital management agreed that participant observation was the most acceptable type of observational data collection for the workplace. They did not feel that it would be appropriate or culturally acceptable if I was seen to just be 'watching' patients and clinicians. They preferred me to have an active role whereby I was seen to be 'working together' with the midwife or CHN. As I have midwifery and child health qualifications, I was able to assist the midwives or nurses whilst undertaking observations as opposed to sitting independently and observing the situation. The type of assistance that I provided the staff during my observations was not directly related to direct patient care. I would often be asked just to document findings or restock supplies. Clients of the

health services were informed of my role as a researcher if I was present during a consultation or on the hospital wards.

### **3.5.2 Retrospective cohort study**

Handwritten community birth records (CBRs) were accessed in both HCs to obtain the initial data on the women who gave birth in 2004–2006. These birth records were used by HC management, the midwives and CHNs.

The inclusion criteria for the study was: all Aboriginal women from the two communities who gave birth to an infant of at least 20 weeks gestation or at least 400 grams birth weight, from 1 January 2004 to 31 December 2006 at the regional hospital, in transit to hospital, in their resident community or a hostel. The infants of these women were also included in the study.

In Community A, infant names, their date of birth and their mother's name were taken from the CBR. Missing data and the identification of stillborn infants were confirmed with the HC manager, as birth outcomes were not routinely recorded in the 'birth book'. In Community B, birth records maintained by the local midwife were used to identify the mother's name, her infant's date of birth and the birth outcome. Data were crosschecked against a record of infant names, their dates of birth and community of residence that was used for the child health service within the HC. The cohort was constructed through manual data linkage between CBRs and medical records at the regional hospital. The common health record number was also used to link records at the HC and hospital, although on many occasions this was inaccurately recorded on the HC records. Maternal records were matched to infant records and data were collected using manual review of records at both sites.

Four hundred and forty-eight women gave birth during the study period. Of these women (and their infants), 26 were excluded as they were non-Aboriginal and two were excluded as the woman gave birth to her infant in a hospital other than the regional hospital.

Four hundred and twenty women and 424 infants were identified as eligible for the study. Eight of these women and 11 of these infants had no community or hospital record available and were excluded. The final cohort consisted of 412 women and their

matched 413 infants. All 412 women had a medical record for available for review at the hospital review; 399 had a medical record available at the RHCs.

Of the infants, 399 had both hospital and community records available for review, 9 had a hospital record only and 5 a community record only (all born in community and never admitted to hospital). In total, 408 infant records were available for review at the hospital and 398 at the HCs.

Maternal data collection commenced on the date of the woman's first presentation recorded during the AN period and ceased at one year postpartum or the date the mother died. Infant data collection commenced at birth and ceased on the day the infant turned one year old or the date the infant died.

### **3.5.3 Missing medical records**

A small number of maternal and infant records were unavailable for review at the hospital or HC. The names of the women and infants with missing records were presented to the HC manager and other staff who had worked in the HC during the 2004–2006 in an attempt to account for the missing records. It appeared that some of the records were missing at random and some had been archived if the woman or infant had not used the HC in the previous two years. Staff identified that most of the women or infants who had not used the HC for an extended period of time were residents of the community who split their time living between Darwin and the community or they lived in other various remote communities, usually because of family relationships, and only visited their home community and accessed local health services very occasionally.

Stillborn infants (n=3) did not have their own medical record; their birth data was accessed from the mother's record. Two of the four infants who died within the first year did not have RHC records available for review, as the records were archived and inaccessible. It also seems likely that some of these infants' records that were not available at the hospital or HC were also missing at random despite repeated attempts to access this information.

## **3.6 Research Instruments**

### **3.6.1 Qualitative instruments**

The Safe Motherhood Needs Assessment [32] was used as the basis for the interview guide (Appendix 8) and the observational checklists (Appendices 10–11). Content of these instruments was also adapted from other health service assessment tools [13, 33]. The 'PaJMA' patient journey modelling tool [22] was used as the framework for the development of the graphically-based patient journeys (Appendices 12–13).

### **3.6.2 Quantitative instruments**

Maternal and infant data collection forms (Appendices 4 and 6) and protocols (Appendices 5 and 7) were developed to obtain demographic, health outcome, anthropometric, health screening, management and service use data from the retrospective cohort study.

Data variables selected for inclusion were predominantly based on indicators designed by the *1+1* researchers, together with an advisory group, to measure health outcomes among remote dwelling Aboriginal women and infants and remote health service delivery and performance [34-35]. Additional variables included in the data collection were derived from CARPA and WBM guidelines and the NT Midwives Data collection.

## **3.7 Analysis**

### **3.7.1 Data entry and cleaning**

Quantitative data were recorded on paper-based data collection forms. Following the completion of data collection at the RHC and hospital sites, data were visually checked and entered into an Access™ (Microsoft Corporation) database designed for the study. Data was then cleaned using STATA™ 11.1 (Statcorp, College Station, Texas) [36]. Rigorous care was taken to ensure the correctness of data entry as data was transferred from paper record into the Access database. Systematic data cleaning was undertaken, including double validation of clinical records by a co-researcher on the *1+1* study.

### **3.7.2 Quantitative analysis**

Statistical analysis was undertaken using STATA™ 11.1 (Statcorp, College Station, Texas) [36]. Continuous data were reported as means (1 standard deviation (SD), 95% Confidence Interval (CI)) or medians (Interquartile Range (IQR)) and in Paper 1, compared using 2-tailed t-test assuming unequal variances if appropriate. Dichotomous data were reported as proportions and in Paper 4, compared using  $\chi^2$ -test. Wilson confidence intervals were reported for binomial proportions. In Paper 4, data were analysed per infant and per presentation to the RHC and hospital. In Paper 5, Z-scores based on WHO Child Growth Standards were derived using WHO published software for STATA [37].

### **3.7.3 Qualitative analysis**

Interviews were tape recorded with the participant's consent and transcribed *verbatim* along with observations and field notes. Pseudonyms were used to protect anonymity. The transcribed material was analysed using content analysis in ATLAS™ T.I 5.4 (Scientific Software Development GmbH, Berlin, Germany) [38]. The transcription analysis identified issues and themes in the data and codes were assigned to units of meaning apparent in each paragraph or sentence. Data were then consolidated into higher-level categories and core themes identified. Content analysis was then undertaken to ascertain frequencies evident within the core themes. Separate analyses were undertaken with different samples of interview participants dependent on the question of interest, which explains the variation in the interview participant samples in the papers.

## **3.8 Ethical Considerations**

### **3.8.1 Consent**

The stakeholders identified as possible interview participants were informed about the study in person by myself and via an information sheet (Appendix 2). If the stakeholders agreed to be interviewed, they were required to sign a consent form prior to the commencement of the interview (Appendix 1). Participation in the study was voluntary and subjects could refuse to participate or withdraw without any negative consequences. Formal consent was not required for observational data collection,

however clinicians and community members who were present during the observations were offered an information sheet (Appendix 3) that outlined my role as a researcher and details of the study.

It was not possible to obtain individual consent from each individual mother and her infant included in the retrospective cohort study due to prohibitive costs, time and logistical constraints of locating a very large cohort of women who live in such remote and highly mobile communities. The Medical Superintendent of the regional hospital, the Head of the Remote Health Services Unit at the Department of Health and Community Services (DHCS), the remote community health board and regional councils and the ethics committee granted permission to undertake the medical record data collection without individual consent.

### **3.8.2 Confidentiality**

All interview subjects were identified via a letter code and not by name. The subjects' names were not disclosed beyond my two co-researchers who had worked together with me to develop the list of stakeholders. No individuals were named in field notes collected during observations or following interviews. Medical record data was required to be collected initially in an identifiable form to link mother and infant records in the hospital and HCs. Following data collection, the data was de-identified prior to analysis to ensure that confidentiality was protected. Individual communities were not named in this study at the request of the communities themselves and are referred to as Communities A and B. Data was aggregated across the two communities for the presentation of results.

Audio tape recordings of interviews were destroyed following the data transcription and analysis. All transcriptions were saved onto a computer whereby access can only be obtained through password security. All paper-based data collection forms, interview transcripts and field notes continue to be kept in a locked filing cabinet.

All data kept on computer is accessible only via password-protected files and accessible only to researchers specifically approved by the ethics committee. Following the completion of this study, all data will be securely stored at the University of Sydney for a minimum of five years in accordance with university Human Ethics Guidelines and the Australian Code for the Responsible Conduct of Research [39]. It is anticipated that a

five-year period following the publication of the research will allow sufficient time in case of requirement for further discussion, data analysis, possible further research, future publications and policy drafting. At the end of the five-year storage period, all original data sources will be destroyed.

## **2.11 Summary**

This chapter provided a comprehensive explanation of the research design and methods used for data collection and analysis in this study. An overview of the mixed methods framework was outlined along with an explanation of each of the framework components; the retrospective cohort study, key stakeholder interviews, observations and patient journey modelling. Further details of study methods and analysis are provided in the methods sections in each of the papers in Chapter 5. The following chapter presents a description of the 'patient journey' undertaken by mothers and infants from the two remote communities in this study.

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# **CHAPTER 4 RESULTS: THE ‘PATIENT JOURNEY’ THROUGH THE NORTHERN TERRITORY HEALTH SYSTEM**

## **4.1 Introduction**

This chapter provides a description of the processes and practices involved in the delivery of health services to Aboriginal women from Communities A and B and a woman’s movement or ‘patient journey’ through the NT health system, during pregnancy, birth and the first year postpartum in 2008. The delivery of health services to Aboriginal infants from these communities and an infant’s journey through the NT health system during their first year of life is also outlined.

This chapter also provides the context for the detailed analysis of the quality and use of these services by Aboriginal women and infants from the two communities. This analysis is presented in the papers contained within the subsequent results chapter, Chapter 5.

Separate descriptions of the RHC services have been provided for Communities A and B, given their individual differences in service organisation and delivery. Both communities use the same regional hospital service, therefore an overarching description of the hospital service has been provided that is inclusive of the experience of women and infants from Communities A and B. The chapter has been divided into the major episodes and transitions in care as it relates to women and infants from these communities.

## **4.2 Data Collection**

The data used to describe the health service delivery and patient journey was drawn from the 60 qualitative interviews, participant observation and field notes made during the observation and interview process reported in the previous chapter. Data collection in the remote communities occurred over six visits to Community A and five visits to Community B. Each visit ranged in length from 3–6 days. Data collection at the hospital occurred over 12 visits.

Clinicians from the RHCs and the hospital validated the patient journey described here and the pictorial version of the journeys (Appendix 12 and 13), as being representative of the majority of women and infants from the two communities. The validation process occurred during subsequent remote community visits and during an Advisory Group meeting in Darwin held in October 2008.

The processes and practices, guidelines, time measurements, clinicians' roles and model of service delivery that are outlined in the results section of this chapter, were accurate at the time of data collection from January–August 2008. Many health system changes that have arisen since the data collection period and have changed mothers' and infants' experiences from the two remote communities. These changes will be explicated in Chapter 5: Results and Chapter 6: Discussion.

### **4.3 Pregnancy, Birth and Postpartum Patient Journey**

#### **4.3.1 Community A: Standard patient journey**

##### **4.3.1.1 Antenatal period: 1<sup>st</sup> presentation to the remote health centre for confirmation of pregnancy and 1<sup>st</sup> antenatal visit**

The journey into the health system for the majority of Aboriginal women from this community typically commenced with a visit to the HC in the second trimester to confirm their pregnancy and commence ANC<sup>2</sup>. The women would present for care following the advice from female family members who are aware of her pregnancy or women may present on their own accord. Female AHWs also reported being informed about a pregnant woman in the community from the woman's family members and they would sometimes go to the woman's house and encourage her to attend the HC.

Most women presented for the 1<sup>st</sup> visit to the HC alone or with their young children. Younger or primiparous women more commonly presented with an older female relative who would also act as an interpreter if needed. Women seldom attended with their partner.

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<sup>2</sup> Some women, a minority in this study, never attend the HC for ANC but only present towards the very end of their pregnancy or when they are in labour.

Some women who presented to the HC for non-pregnancy related issues had their pregnancy confirmed by a RAN, who sometimes had midwifery skills or an AHW or DMO. The woman's pregnancy status was documented in her notes by the clinician and the woman was then referred to the midwife for ANC and to a DMO if required. During this visit some clinicians would take routine AN blood tests and prescribe folate and vitamins according to local guidelines in the WBM (3<sup>rd</sup> edition), although this was an inconsistent practice.

Most woman would present directly to the 'Women's Area' of the clinic when they required pregnancy care and wait to be seen by the midwife, who was the main provider of maternity care in the HC. The midwife was available on two set days per week to provide ANC and PNC and spent the other days during the week providing 'Well Women's Checks' (which include pap smear screening, breast checks, STI screening and follow up), adult health checks and other general nursing services. The midwife also provided health education occasionally at the school as well as providing 'on call' services for emergencies after hours.

Aboriginal Health Workers infrequently provided ANC together with the midwife. It was dependent upon the busyness of the rest of the HC as to whether the HC manager would assign an AHW to work with the midwife. If there were patients with acute presentations waiting to be seen, the AHW was often be required to work in the emergency department of the clinic instead of with the midwife.

On presentation to the 'Women's Area' of the HC, the midwife, AHW or administrative staff retrieved the woman's patient record from the main filing room. If the woman was visiting from another community, the midwife would ring her home community HC to have information about her past medical and obstetric history faxed. It was a complex and time consuming task to retrieve information from another HC, often involving repeated phone calls for clarification of information and up to one hour of the midwife's time.

The midwife or AHW then confirmed the pregnancy with a urine test. Following this, they would usually would undertake the 1<sup>st</sup> AN assessment according to the guidelines outlined in the WBM. A medical and obstetric history, physical assessment, pathology and other tests were taken as indicated in the WBM and findings documented on an AN

record, which would be filed within the medical record. Women were not routinely given their own copy of their handheld medical record to keep. It is recommended in the WBM that all women should be seen by a doctor for a medical review early in their pregnancy however this seldom occurred given the very high workload of the DMOs treating acute presentations and providing chronic disease management.

Once the woman had completed her AN appointment, the midwife (or the DMO if she saw them following the midwife) would then recommend a time for the woman to return to the HC for ongoing AN appointments with the midwife and/or DMO. They would record the woman's pregnancy details, next appointment date and any follow-up tests and appointments that were required in the medical record. The midwife also kept a detailed diary of all the women who were currently pregnant in the community and when they required their next visit.

The relevant test request forms to accompany the routine pathology and other tests were then completed and pathology and other specimen transport organised. The midwife would also routinely complete a request form for an ultrasound to be undertaken at the regional hospital and a request letter for an AN appointment to be undertaken during the same visit at the hospital<sup>3</sup>. These documents were then faxed to the regional hospital so that a time and date could be booked for the woman's appointments. Once the hospital AN clinic received the appointment requests, the AN clinic administrative staff would usually fax appointment details back to the HC. This could take up to one week. This information was then passed from the administrative staff at the HC to the midwife, although this passing on of information was inconsistent and often the midwife had to spend time searching for this information herself at the reception desk.

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<sup>3</sup> Morphology scans, growth scans and monitoring of twin pregnancies, placenta praevia and other complications were undertaken at the regional hospital. Dating and presentation scans were usually performed by the visiting ultrasound service. However, if there was uncertainty about a woman's gestation at the first visit and there was no visiting ultrasound service for a number of weeks, the midwife could also book the woman a dating scan at the regional hospital. Due to the busyness of the ultrasound service, some women would wait up to one month for this ultrasound appointment. The cost of flying women for a dating scan on a commercial airline to and from her community was approximately \$500 in 2008.

#### 4.3.1.2 Ongoing antenatal care

The midwife provided ongoing ANC throughout the pregnancy at the HC. There was no home or community-based ANC. In addition to providing midwifery care to the community members, the midwife was responsible for organising and coordinating all hospital appointments and travel arrangements to the regional centre so that a woman could access hospital services. Administrative tasks – which included time spent ringing the hospital or other HCs for patient information, locating pathology, organising appointments and faxing documents to the hospital – accounted for up to 30% of the midwives' time in both communities. Most women would be transferred into the regional centre for a morphology scan in the 2<sup>nd</sup> trimester and then again at around 36–38 weeks for the remainder of their pregnancy care and birth at the hospital.

When the midwife had received the antenatal appointment details back from the regional hospital, she could then complete a Patient Assisted Travel Scheme (PATS) request form to book the flight to the regional centre to attend the hospital appointments, accommodation and transport in the regional centre and, if eligible, permission for the woman to have an escort accompany her. The midwife was then required to locate the DMO and have them sign the request form, which was usually another very time wasting process for the midwife. The midwife, or on occasion an administrative staff member, would then fax the form to the PATS office in the regional centre for processing<sup>4</sup>.

Once the PATS request had been received from the HC and approved, PATS would fax a travel itinerary back to the HC as well as to the airline, hostel, AIMS (designated bus service in Darwin for patients of the regional hospital) and the hospital AN clinic. When the midwife in the community received this information she was required to inform the woman of her travel details. This was a time consuming process if it was not able to be

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<sup>4</sup>The PATS service provides some financial assistance to NT residents who are required to travel more than 200km to access a hospital or specialist medical services not available in their community. Primiparous women or those aged less than 16 years were eligible for PATS assistance to have an escort accompany them throughout for their hospital journey. Many other women, however, who were in need of escorts (such as women who did not speak English as a first language) were not automatically entitled to this financial support and required the DMO to submit an additional letter to PATS requesting this support.



done during an AN visit as it involved the midwife driving to the woman's home, usually after normal work hours, to inform her of the travel details. If she was not there, the midwife would search for her across the community until she could pass on this information.

The midwife would book the woman into the HC diary so that the HC driver could pick her up from her home on the morning that she was required to travel. The midwife was also required to fax a full copy of the woman's AN record and other test results to the AN clinic prior to the woman's transfer to the regional centre. Some clinicians would give the woman copies of her own AN record to take to her appointments at the regional hospital, although this practice was inconsistent.

Observations showed that the midwife often did not receive the necessary appointment or travel information from the hospital or PATS, which required her to make multiple phone calls to obtain this information. There was also a delay in the midwife receiving this information at times from the HC administrative staff.

Health centre clinicians stated that there was no effective system in place to ensure that faxes, pathology or other test results and other administrative documents were passed on to the midwife or DMO when they arrived at the HC. The midwife or DMO would often be required to check the mail and faxes after hours to ensure that they had not missed out on receiving any important patient documents.

#### **4.3.1.3 Pregnancy care for women with complications**

If any comorbidities or pregnancy complications were detected at any time during the pregnancy, the midwife would discuss the case with the resident DMO for management advice. Depending on the nature and urgency of the problem, the DMO would undertake a medical review at that same visit if possible or request that the woman return for a further visit on another day. If the woman required more complex medical treatment than could be provided at the HC or urgent hospital care, the woman would be evacuated to the regional hospital where she was admitted as an inpatient. Following inpatient treatment, the woman could then be sent home again for ongoing AN care with the DMO and midwife. It was sometimes decided however by the hospital medical team that it was more appropriate for her to stay in a hostel in the regional centre from an early gestation and have all ongoing AN care at the regional hospital through the

'High Risk Antenatal Clinic'. This could mean weeks or months away from her family, including her own small children if she had any.

Other women who were identified with obstetric or other medical complications during pregnancy were often managed in the community by the midwife and DMO and flown regularly into the regional centre for care in the High Risk Antenatal Clinic and/or other specialist physician clinics at the hospital. The midwife or DMO would directly contact medical or midwifery clinicians at the AN clinic if an urgent appointment was required, although it was often difficult and time consuming for the remote clinicians to make direct contact with AN clinic staff. Most of the time a referral letter was faxed to the AN clinic to request an appointment for the High Risk Antenatal Clinic and the appointment time and date was faxed back to the HC within a few days. This was variable and sometimes required the midwife to make multiple phone calls to obtain this information.

In addition to hospital appointments for women with identified complications, the visiting obstetrician and/or obstetric registrar and a women's health nurse from the regional centre would also provide ongoing pregnancy care at the HC. Their input was minimal, however, as they would provide outreach services to the community a few times each year. The team would usually visit for a day or two at a time and provided specialist care and ongoing management plans.

#### **4.3.1.4 Transfer to the regional centre for pregnancy care**

On the day that a woman was booked to travel to the regional centre, the woman (and her escort if deemed eligible by the DMO and PATS criteria) would usually be picked up from home by the HC driver, transported to the airport and then flown to the regional centre on a commercial flight.

When the woman arrived at the regional centre airport, she would need to locate the AIMS bus driver who would provide transport to her private or hostel accommodation or to the hospital if the woman had an appointment or ultrasound scan that same day. The AIMS driver would have a copy of the patient itinerary that included details of the woman's flights, accommodation address and hospital appointments. Buses travelled to and from the hospital four times each day. If the woman missed the bus, she would have to wait for the bus to return which may be a couple of hours or pay for her own taxi

from the airport to the hospital, which in 2008 was around \$20. There was also a two-bag limit for each passenger travelling on the bus and if this was exceeded, the woman would not be able to use the bus service and was required to pay for her own taxi to the hospital or her accommodation.

#### **4.3.1.5 Antenatal appointments at the regional hospital**

Once the woman arrived at the hospital she would often present to the Aboriginal Liaison office if she was unfamiliar with the hospital and the Aboriginal Liaison Officer (ALO) would be able to take her to the scheduled appointment. At the AN clinic, the woman would meet the receptionist and give her a copy of her AN record if she had been given a copy and carried this. The receptionist would note the arrival time at the clinic, check the woman's contact details, obtain the faxed copies of her AN notes and test results from her HC and the hospital record (if she had been a previous patient at the hospital) and give the woman directions to the waiting area.

If there were no AN records available from the HC, reception staff would attempt to contact the HC and have these documents faxed through to the clinic. This process would often delay the woman's appointment, especially if the documents could not be accessed at all, despite requests from the hospital clinicians; patient data and pathology tests were often duplicated as a result.

Women would wait in the waiting area until called by a midwife. The midwife would welcome the woman to the AN clinic and usually check the weight and height of the woman before entering the "first visit" room. The midwife would then check details on the AN record, chase results of blood tests, ultrasounds and other tests if these results were not documented in the AN record, take a blood pressure and urinalysis and complete domestic violence screening (at the 1<sup>st</sup> hospital visit). The midwife would then explain different roles of the health clinicians and give written pregnancy information. If the woman did not speak English and did not have anyone with her who could act as an interpreter (family member, ALO), the midwife could call the ALO to see if there is anyone available who could speak the same language as the women and organise for them to be present during the AN visit. At other times, no interpreter service was available and women and staff would just attempt to communicate as best as possible.

The woman would then return to the waiting room until called by a doctor. The doctor would review test results, provide ANC and forms for any upcoming tests and give the woman instructions as to how and when to book the next appointment and which clinic she should attend. If the woman required a CTG or other tests on the same day, the doctor would direct the woman back to the midwife and she would assist the women in completing these tests. On occasion, doctors in the clinic would undertake additional ultrasounds.

Once the AN appointment was finished and any additional tests were completed, the woman would return to the reception desk where her departure time would be noted and her next appointment would be booked. Appointments could take a whole morning or afternoon if additional tests or investigations were required but were generally completed within two to three hours. There was no system in place for continuity of carer within the hospital AN clinic, so each time a woman attended a hospital appointment she could be seen by different medical and midwifery clinicians.

Sometimes women arrived late to their appointments or presented on the wrong day. As a result they were often required to rebook the appointment for a different day thus delaying their return to their home community and increasing their personal expenses associated with staying in the regional centre. Some women would choose not to return to the hospital for the appointment and fly back to their community without having had the planned pregnancy care or tests.

If a woman was booked for an appointment but failed to attend, AN clinic staff would record this in the woman's hospital record and then contact the ALO to inform them of the non-attendance. The ALO would then attempt to contact the hostel or private address where the woman was staying to find out where the woman was and organise for the appointment to be rescheduled. The AN clinic staff would also try to inform the RHC of the woman's non-attendance at her appointment, although this was often inconsistent.

On completion of the woman's appointments and tests at the hospital, the AN clinic reception staff would either ring PATS to let them know that the patient attended the appointment or the women or the ALO could present to PATS themselves to say the

appointment had been completed. Flights were then booked by PATS so that the woman could return to the community. This was usually on the following day<sup>5</sup>.

#### **4.3.1.6 Return from regional centre to home community for ongoing pregnancy care**

Once a woman had her travel details completed, she would wait for the AIMS bus to arrive and be returned to her accommodation. The bus would again collect the women prior to her flight, transport her back to the airport where she would catch her flight back to her home community. There she would have ongoing ANC until she was transferred into town for further AN visits, usually only required if there was a complication identified later in pregnancy, a test needed that could not be undertaken at the HC or once the woman was around 38 weeks pregnant to await birth.

Remote health centre clinicians identified that there was poor communication by hospital AN staff regarding ongoing management and treatment of pregnancy issues and outcomes of AN visits. Remote clinicians identified that they did not regularly receive a copy of the AN record with the documentation of the hospital visit details; neither did they receive adequate verbal handovers from hospital clinicians about a woman's outcomes or if a woman was going to be admitted as an inpatient.

#### **4.3.1.7 Transfer from home community to regional centre to await birth**

When a woman was around 34 weeks pregnant, the midwife would fax a request letter to the AN clinic for a 38 week AN appointment (or earlier if there were pregnancy problems, previous premature births, etc.). The woman would stay in Darwin following this 38-week AN appointment until after she had given birth. Once the appointment dates and times were faxed back to the midwife at the HC, a patient travel form (and escort request if required) was completed by the midwife, signed by a doctor and faxed to PATS.

Once the travel itinerary was received by the midwife, she would inform the woman of the travel arrangements and also fax a full copy of the AN record and relevant pathology

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<sup>5</sup> If flights were heavily booked or unavailable due to weather conditions, some women could remain in Darwin for a few days following the completion of their hospital appointment. Further accommodation in Darwin was booked at that time by PATS if required.

and ultrasound reports to the AN clinic. The midwife would enter the woman's travel details into the clinic diary so that she could be picked up on the day of travel and transported to the airport. Some women organised their own travel to the airport.<sup>6</sup>

The same processes for travel to Darwin and presentation at the AN clinic were followed when women were seen at 38 weeks, as outlined previously. (However there was no flight booked for return to their home community until after a woman gave birth). Remote clinicians reported that women occasionally returned to their community unofficially during this period. These women were usually identified as 'missing' by staff at the hostel where the majority of women usually resided for up to three–four weeks before and after their babies were born. Difficulty accessing transport to shops as well as a lack of known support from family and friends, personal safety issues, boredom, loneliness and lack of activity were among the issues identified by clinicians and hostel staff about the hostel stay. Some women paid their own way back to their community prior to having their baby to avoid or minimise this experience.

#### **4.3.2 Community B: Standard patient journey**

Antenatal care was provided in the Community B HC five days per week. The same processes were generally followed in terms of women presenting for pregnancy confirmation, providing pregnancy care and patient travel bookings. However, in comparison with Community A, Community B provided more administrative staff as well as support and assistance for the midwife with the organisation of documentation and faxing for appointments, filing of reports and handover of information, such as appointment times and dates from the regional hospital.

Although Community B had more time available to undertake administrative tasks and more efficient administrative support and systems in place than Community A, Community B midwives still encountered difficulties accessing AN clinic staff at the

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<sup>6</sup> Health centre clinicians identified that some women would go 'missing' from the community at around 35–36 weeks or immediately before boarding the plane to avoid being transferred into the regional centre for birth. Family issues such as lack of child care for other children remaining in the community, money issues, cultural commitments and previous negative experiences with the hospital were reasons commonly cited by HC clinicians as to why women did not get transferred into the regional centre when planned. Some of these women would then present to the HC in labour and require an emergency air evacuation to the hospital or they would go on to deliver in the community.

regional hospital to make patient appointments and faxing documentation. (The fax was often engaged, requiring staff to repeat the process of trying to fax notes a number of times during the day until it was received by the hospital.)

Community B also identified that there was a lack of communication between the hospital clinicians and the HC clinicians when women were discharged following an AN admission or when they were seen in the AN clinic. Copies of patient notes or discharge summaries were often received a number of weeks or sometimes months after the patient returned to the community or not at all. Consequently some women missed out on receiving important follow up in the community, additional tests or medication, as there had been no handover of this information.

Information recording systems differed between Communities A and B. Community A used the patient file as well as the AN record as the main recording documents during pregnancy. Community B had the Primary Care Information System (PCIS, an electronic database) introduced in 2008. Clinicians were required to fill out a paper-based AN record as well as the PCIS system at every visit. The information recorded on the AN record was data that was duplicated on the PCIS system.

#### **4.3.3 Regional hospital care**

A woman was seen weekly at the regional hospital AN clinic following her transfer to Darwin at around 38 weeks. She would be picked up from her accommodation by the AIMS bus and transported to the AN clinic. The same processes outlined previously for attendance at AN visits (under 'travel to Darwin' section) were followed. Once the woman attended her appointment and had any further tests or appointments booked, she would then wait for the AIMS bus to return to her accommodation.

#### **4.3.4 Labour and birth**

When a woman would go into labour, it was common for the woman herself or her escort to inform the hostel caretaker or manager that she needed to go to hospital for birth. The hostel caretaker would call the labour ward on the woman's behalf to notify them of the situation, the woman's details and planned transport arrangements. The hostel staff usually called an ambulance to transfer the woman into hospital. Some women organised their own transport into hospital (taxi or family).

Once the woman arrived at hospital she would present either to the ALO office (if presenting during business hours) and an ALO would accompany her to a birth suite but not provide labour support. Most women would not have an accompanying known support person during labour if they were not eligible for an escort. A midwife, who was usually unknown to the women, would take the woman into a birth suite room and enter the woman's details into an admission book. The woman would give the midwife a copy of her AN record if she had this and the midwife would ring medical records to request the patient record or enters details into an electronic hospital record system to request this record.

The midwife would then call the Patient Care Attendant (PCA) to collect the medical record. If the woman did not have a patient record at the hospital and if there was no AN record available from her home community, pathology and other tests would often be repeated and duplicated as part of the admission process. The busyness of the birth suite often prevented clinicians' from having time to ring the home community HC and access AN records.

The midwife would then assess the woman. If she decided that the woman warranted admission, she would ring the AN/PN ward clerk to admit the patient (if after hours, a phone call would be made to the emergency department triage for admission). The midwife would also inform a doctor (usually the resident) of the woman's admission and they would also usually meet the woman and undertake another assessment and an admission history. Following these initial assessments, if the midwife or doctor decided that the woman was in early labour or did not need to be admitted to the birth suite, the woman could be sent back to her hostel and she would return to the hospital usually via ambulance when in established labour<sup>7</sup>. The woman might also be sent to the AN/PN ward to establish labour if she was multiparous, had a past history of precipitous labours or had a complicated pregnancy.

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<sup>7</sup> Hostel staff identified that some women were discharged from hospital in early labour, then would wait up to 2 hours for the AIMS bus to take them back to their hostel, arrive at the hostel in established labour and then require the hostel staff to organise ambulance transport back to the hospital again. On a few occasions, reported to myself, women gave birth at the hostels without a skilled maternity care provider. Hostel staff also reported that they very often provide patient care services beyond their role, such as organising ambulance transport and supporting women in labour.



Once the woman was admitted to the birth suite in established labour, care was provided by a midwife and sometimes a midwifery or medical student with doctors providing medical care as needed. These clinicians may have been different from the clinicians the woman met initially if she presented in early labour and was sent home. Both medical and midwifery clinicians were usually involved in providing some aspect of the labour care (admission assessment, vaginal examinations, etc.), much of which was duplicated.

Women often received care from numerous clinicians whom they had never met before. There were multiple care handovers and numerous shift changes throughout the day: midwives – three handovers per 24 period; resident doctors – two or three in a 24 hour period; registrar or consultant usually two in a 24 hour period. If a woman required medical intervention (narcotic/epidural analgesia, induction, CTG monitoring, etc.) during her labour or if she had a complex pregnancy issue, her care would involve many more caregivers, such as senior obstetric doctors, anaesthetics and/or paediatric doctors as opposed to women with spontaneous labours and no intervention who were predominantly cared for by midwives<sup>8</sup>.

After a woman gave birth in the birth suite, the midwife (and sometimes medical clinicians) provided early PN care to the mother and infant. The midwife updated the maternal records and commenced new infant records, including infant progress notes, observations and registered the birth. Postnatal care was usually provided in the birth suite for a couple of hours following birth. Following the completion of the paperwork and the initial PNC of the mother and infant, the midwife would ring the PN ward and provide a verbal handover of the mother and infant to the unit manager or another midwife. The mother and infant would then be transferred to the PN ward.

#### **4.3.5 The postpartum period: Hospital**

After birth, the midwife caring for a woman in the birth suite would then provide a verbal handover to the midwife taking over the care on the PN ward. They would also hand over the mother and infant records at this time. The mother and infant were cared

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<sup>8</sup> If a woman required transfer to theatre for a caesarean section, care was provided by the midwife, obstetric staff, an anaesthetist, theatre nursing staff (admission, perioperative, recovery), paediatric staff and a PCA this could result in 10 or more clinicians being involved for a theatre procedure.

for on the PN ward by a multitude of midwifery, nursing and medical clinicians, again most often unknown to the woman. Most women were visited by the ALO during their PN admission and they assisted her with the completion of the birth forms required for formal registration of the baby and government payments for new parents. Midwives and registered nurses provided the majority of the patient care for women although the frequent shift changes and restrictions on the procedures and care that registered nurses could provide to pregnant and PN women and infants results in fragmented care and multiple care handovers.

Most women stayed in hospital for three nights following a vaginal birth or four following a caesarean section. However, the length of PN stay for mothers and infants varied according to their needs and availability of hostel accommodation or self-care accommodation at the hospital (provided for mothers with babies in the neonatal nursery). Sometimes women would have their inpatient stay lengthened if there was a lack of available hostel accommodation, airline delays or airline restrictions. One airline did not allow infants to travel under a week old unless the mother had a letter of authorisation from a medical doctor.

Doctors would review the women prior to a decision being made for discharge. Once this decision had been made, midwifery or medical staff would inform the ward clerk of the discharge plan. The ward clerk would inform PATS of patient discharge details and PATS would book accommodation (if required) and flights home. The itinerary was then sent from PATS to the ward, hostel and AIMS. Once these details were confirmed, the woman was informed of the discharge plan by the ward clerk and the midwife and the discharge paperwork (mother and infant summaries) were completed by midwifery and medical staff. These staff may not have cared for the woman previously but were assigned the task of completing the paperwork. Prior to the woman leaving the hospital, the summary was supposed to be sent to HC and a copy given to the woman<sup>9</sup>. However, this was also inconsistent practice and observations confirmed this was infrequent.

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<sup>9</sup> If a baby was admitted to [need to define SCN first; only occurrence of abbreviation] SCN following birth, a nursing discharge summary, photocopies of relevant notes and paediatric discharge summary were supposed to be sent back to an infant's home HC in time for arrival home. The paediatric resident might also ring the infant's home HC to hand over and discuss discharge plans but this was reported to be an irregular practice and dependent upon the individual doctor.

If the woman was being discharged before the third day following a vaginal birth or five days following a caesarean section, and she was not immediately returning to her community on the day of discharge, she was eligible for Midwifery in the Home (MITH), a community-based domiciliary service. If the woman wanted this service, the midwife discharging the woman from hospital would hand over care to the MITH clinicians via a written referral. A home visit was subsequently organised by the MITH staff. They are not part of the core PN hospital staff and are unknown to the woman. Observation showed this could be up to the 25<sup>th</sup> different clinician to be allocated to a woman's care since entering the hospital system for birth.

#### **4.3.6 Discharge from hospital: Awaiting return to home community**

Once the woman and her infant were discharged from the PN ward, they would usually be picked up by the AIMS bus service from the regional hospital and either taken to the airport to fly directly home on the same day or stay at a hostel or with family or friends until the day of their flight.

Women who were discharged from hospital early could receive a MITH visit at their hostel or private accommodation. If the woman and her infant were still in Darwin around the 10<sup>th</sup> day post-birth, they might also receive a visit from the CHN who worked for the Community Care service. The MITH and Community Care staff would fax the discharge summaries from their services back to the home community HC once they had ceased their visits with the woman. It was identified that many remote dwelling women did not receive any domiciliary care in the regional centre post-hospital discharge. Women commonly denied the service were discharged after the cut off for MITH eligibility and then travelled home before day 10. Sometimes this occurred because of communication issues between the woman and domiciliary midwives. There could be confusion around expected dates and times for home visits or women were not contactable on mobile phone numbers or addresses provided to the domiciliary midwives.

#### **4.3.7 Transfer from regional centre to home community**

Once a woman and infant returned to the community via commercial airplane, she could present during that same week to the HC for a PN check, although this was variable. Around 40% did not present at all during the six months after their baby was born.

Many only presented if there was an acute illness or if they required contraception from the DMO. Neither RHC had an effective system in place to provide home-based PN care for women.

In Community A, PN care was available to women at the HC on two set days each week. It could also be provided on a third day if the midwife was not busy running the 'Well Women's Clinic'.

In Community B, women could present for PN care five days per week. Both communities identified that it was very difficult to follow up women who did not present at the HC for PN checks as the high workload associated with providing ANC often consumed the majority of time allocated for the midwifery service. Midwifery staff were often unaware that a woman had given birth and been discharged from hospital until the woman presented for a PN check or would bring the baby to the HC to show the staff. Sometimes clinicians received a copy of the discharge summary (although this was usually well after the woman had returned to the community). Very occasionally mothers were referred for a PN check by the CHN if they had seen the infant, who had typically presented with a health problem.

A woman usually presented directly to the midwives clinic room for a PN check. The patient file was retrieved from the midwife clinic room (it was usually stored there during the AN period and once the woman had been transferred to hospital for birth). If the file was not available in the midwife's room, administrative staff or an AHW could assist the midwife in locating the file in the main filing cabinets. In Community B, the electronic record was accessed in addition to a patient file.

The midwife or AHW would collect the discharge summary from the woman if she had a copy of this with her or would look for a faxed copy from the regional hospital in the main reception area or filing pile. If the discharge summary was not available, the midwife might attempt to contact the regional hospital for this information. This would usually be done after the woman had her PN check and was sent home, unless there was a particular problem that the woman identified as requiring urgent follow up such as medication, blood tests, etc. This process of retrieving missing information from the hospital was very time consuming. Midwives often undertook this during their lunchbreak or after normal clinic hours due to the busyness of their midwifery service

and need to prioritise providing clinical care during clinic opening hours over administrative tasks.

The midwife (and sometimes the AHW) would conduct a PN check according to the WBM guidelines. If there were no further issues and the woman did not require a medical consultation she was advised when to return for her next PN or well women's check and this was recorded in the patient notes.

If a woman also required a medical consultation at this time, she was referred to the main clinic where her name would be added to a doctor's waiting list by the midwife, AHW or other clinician and her patient record placed in the waiting box. In Community B, the medical clinician reviewing the woman will also access the electronic record.

A medical consultation would be undertaken and if the woman required a further review or follow up, her name would be added to the recall list and the woman would be sent home (or she may be evacuated to hospital if this is required).

The woman would be either picked up by the HC driver on the day requested by the doctor for review or the woman would present to the HC herself. The woman would present to reception and the administrative staff would locate her file and add her name to the waiting list. The woman would wait to be seen by the doctor and a follow-up review conducted.

## **4.4 Infant Patient Journey**

### **4.4.1 Community A: Standard patient journey**

Once a mother and infant had returned back to their home community from hospital after the birth, the mother (or carer) and the infant would usually present to the RHC sometime during the first week for a routine baby check at the 'Child Health Clinic'<sup>10</sup>. Clinicians providing this care did not necessarily have child health qualifications or prior experience working with infants. Clinicians identified that the limited time

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<sup>10</sup> The 'Child Health Clinic' was run two days per week by the CHN, sometimes with the AHW, although this was inconsistent. The clinic mostly provided immunisations, growth monitoring and intervention (weighing, monitoring, feeding education, follow up and treatment for children with growth faltering/failure to thrive), haemoglobin monitoring and anaemia treatment, deworming, skin care and treatment, family support and health education to children under 5.

available to provide 'well child care' to a large population of children under five, often with complex needs, was extremely difficult and there was no option of providing this care outside of the HC. Time spent on preventive health care and health promotion was very limited and observations showed this was often provided ineffectively, especially if there was no AHW to assist with this. Clinicians also identified that there were a large number of infants who required intensive growth monitoring and treatment for growth faltering and failure to thrive during their first year. However, there was inadequate time available to address these issues effectively. Overdue immunisations and complex family issues such as money problems or food access were also difficult to address due to time and resource constraints. There were no active community-based programmes or child health outreach services available for families at the time of data collection.

In order for a mother to receive HC care for her infant, she would firstly present with the infant to the administration desk where a new patient file was created by the administrative staff. Infant details were recorded on the local population record and also entered into the new file. The mother and infant would then go directly to the 'Child Health Clinic' waiting area to see the CHN. The CHN would collect the new file from the administration desk prior to seeing the family.

Some families would give the CHN a copy of the discharge summary if they have been given this at the regional hospital. Alternatively, the CHN would look for the faxed copy of the infant discharge summary from the hospital in the filing pile located in the administration area. If this could not be located, she might phone the hospital following the consultation and ask for this to be faxed, possibly again, to the HC. This was a time consuming process. Child health clinicians identified that they did not often receive discharge summaries from the regional hospital until well after the infant has returned to the community or not at all. If infants were not brought to the HC by a carer for a routine health check when they returned, and if the discharge summary had not been received by the CHN, the CHN was often unaware that the infant was back in the community. Infants may not be seen in that case for a number of months, missing out on immunisations, preventive health care and health education.

Following the retrieval of the file and discharge summary (if possible), the CHN and AHW would then undertake the consultation. If there were no problems found or

identified by the carer, the CHN would recommend a time for a further visit, which was usually based around the GAA schedule and the family would be sent home. If the infant was found to have an acute illness, they were referred to the main clinic and their care would be handed over to either a doctor, RAN or AHW<sup>11</sup>. The infant's name would be added to the waiting list by the administrative staff or CHN and the infant's medical record placed in the consult box.

The infant would then be seen by a different clinician and a decision made for the infant to either be sent home with no further follow up required or the infant would need to be reviewed (usually the following day) or require evacuation to hospital (see below under Transfer to hospital from community).

If the infant required a review their name was added to the recall list and they were sent home. The recall list was given to the HC driver and AHW the following day and the infant and their carer were usually picked up from home and brought to the HC. The carer and infant would present to reception and the infant's name was added to the waiting list by the administrative clinicians. The infant file was then collected and placed in the consultation box. A clinician who was not necessarily the same clinician who saw the infant on the previous day would then review the infant<sup>12</sup>. The clinician would then decide if a subsequent follow-up visit was required. If not, they would usually be referred back to the CHN at a specified time for general ongoing health checks and then sent home.

If further follow up was required, the infant's name would be added to the recall list and the infant sent home. The infant may be reviewed for many days in a row by different caregivers at every presentation for one episode of illness, resulting in multiple discontinuities in care and care handovers.

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<sup>11</sup> If an infant had ongoing or complex health issues, they were referred to the visiting outreach paediatrician who was usually based at the regional hospital. The paediatrician would visit the community on a monthly basis and provided good continuity of carer.

<sup>12</sup> The discontinuity in care that occurs in child health has been identified as a very problematic issue in this community as infants do not necessarily receive the follow up or treatment that they require, even when it is specified in the patient notes from the previous day or file entry.

#### **4.4.2 Community B**

The CHN in the 'child health room' of the RHC saw children from birth to age 5 who presented for 'well child care' or with acute symptoms. One or two nurses staffed the child health room five days a week. If there were a number of unwell infants and children needing to see the CHN, some would be allocated to the main clinic and seen by other RANS or AHWs or if the infant required a medical consultation, they were seen by the doctor in the main clinic and would bypass the child health clinic.

Discontinuity in care existed at times where infants who required additional follow up and reviews were seen by the CHN for their initial acute presentation and then in the main clinic for their review by a different clinician<sup>13</sup>.

The PCIS system was used in Community B instead of a paper-based patient record. As this clinic was part of the initial testing of the PCIS system technical issues caused difficulties when the system was not available and this was identified as a time consuming process for data entry and retrieval of patient information.

#### **4.4.3 Transfer from community to hospital (Community A and B)**

If an infant was seen in a HC by a nurse or AHW and warranted evacuation to hospital, the treating staff member provided a handover to the DMO. The DMO then reviewed the child before a decision for evacuation was made. If no DMO was present in the community, the 'on call' DMO was phoned, usually by the nurse, to discuss the infant's presentation and authorise the evacuation. Following the decision for evacuation, the HC clinicians would continue to treat the infant and prepare paperwork to be sent to the hospital.

The HC DMO would also make a phone call to the hospital paediatric registrar or consultant to inform them of the evacuation of the infant from the community and hand over the details of the infant.

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<sup>13</sup> Clinicians identified that sometimes if a carer presented with their infant for a non-acute reason (immunisation, weight, etc.) and there was a long waiting time because other infants with acute illnesses were being seen by the CHN, the carer and infant would often leave before their consultation.



The paediatric registrar or consultant would then telephone the emergency department triage clinicians and the paediatric ward (or ICU if the infant was expected to be transferred there) and inform them about the evacuation of the infant and patient details. Emergency clinicians would retrieve existing patient records or begin a new file for the emergency admission prior to the infant arriving in the emergency department.

The HC DMO would then telephone PATS and Air Med to inform them of the need for patient evacuation and hand over patient details. Air Med staff then would contact the HC with an estimated time for the arrival of the flight into the community.

The HC staff would continue to care for the infant until the Air Med plane arrived<sup>14</sup>. The infant was either retrieved from the HC by the Air Med clinicians or transported directly to the airstrip for the evacuation.

Health centre clinicians' handover of patient details, notes and a referral letter to the Air Med clinicians. The infant (and her carer if there is room available on the flight) is then transported to hospital. If there is no room available on the flight for the carer, the carer is usually required to wait until the next available commercial flight or charter from the community to Darwin.

Upon arrival at Darwin Airport, an ambulance would be waiting to collect the infant from the Air Med plane. The Air Med clinician hands over the patient details to the ambulance staff and the Air Med nurse or doctor usually accompanies the infant (and the carer) in the ambulance to the hospital.

The ambulance transfers the infant from Darwin Airport to the regional hospital emergency department. On arrival to the hospital, ambulance or Air Med clinicians' would hand over patient details and paperwork to emergency triage clinicians. A triage category may have already been assigned to the infant following the phone handover from the paediatric registrar or consultant prior to the infant's arrival and the infant could be directly transferred to ICU or the ward. Usually the emergency triage clinicians would complete admission paperwork and assign a triage category once the infant arrived in the department.

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<sup>14</sup> Usually there is just a flight nurse and a pilot – sometimes a doctor may also travel to the community, depending on the reason for the infant evacuation.

The infant and carer would then wait to be seen by emergency clinicians (and usually a paediatrician). Clinicians would review and stabilise the infant in the emergency department and then phone the paediatric ward to notify them of the patient transfer.

The infant and carer were transferred from the emergency department to the paediatric ward and a handover given to the paediatric ward staff.

Multiple caregivers on the paediatric ward cared for an infant during their admission, with frequent staff handovers and a number of different clinicians working together to provide patient care (nurses, residents, registrars, consultants, ALO, AHW, outreach paediatrician). There was no system in place for continuity of nursing care in the neonatal nursery or paediatric ward.

Nursing staff handover 3 times per day; medical clinicians handover 2–3 times per day. Paediatricians change over from day shift to night shift; however they provide more continuity of care to patients as they are rostered to work in blocks of time on the ward usually for a few weeks at a time.

If an infant had been seen by the outreach paediatrician in their community prior to their hospital admission, the outreach paediatrician was usually informed about the infant's transfer to hospital. They may not have been directly involved in the infant's care if they were not rostered on ward service but could suggest management options or assist with discharge planning, being familiar with the infants medical history, family and social circumstances, etc.

The decision for discharge from hospital would be made on a ward round by medical staff. This information would then be communicated to the nursing staff and manager and also discussed with the family. The nursing staff and manager would organise the discharge planning and the ward clerk would be informed of the discharge plans by the nursing staff.

The ward clerk would inform PATS of the patient discharge details. PATS would then organise transport and accommodation at a hostel (if required) and forward the travel itinerary to the ward, hostel and to AIMS. The discharge summary may have been completed by medical staff prior to the infant's discharge and sent to the HC at the time of, or within 48 hours of, discharge. Some medical staff would provide a verbal

handover to HC staff when infants with complex issues were discharged home, although this was not routine practice. Remote clinicians identified this as an area for improvement and my observations suggest handover was unusual and records were often delayed. For example, discharge summaries were often not received by HC clinicians for a number of weeks after the infant had returned from the hospital and clinicians were unaware of the infant's discharge from hospital. Infants therefore may have missed out on follow-up treatment, as this important information was not communicated to the HC clinicians.

Other discharge paperwork was supposed to be completed by the nursing staff and medications and supplies organised and given to the infant and carer prior to discharge from hospital. Once this had been finalised, the infant and carer would wait for the AIMS bus and were transferred back to a hostel or to family or friends until their flight home.

#### **4.5 Summary**

This chapter has provided a description of the way health services at the RHC and referral level were accessed and used by mothers and infants from the two remote communities in this study. The processes involved in health service delivery and transfer of care across health care sites have also been outlined. These services were fragmented, and were frequently dangerous and deficient when these observations were made. Women and infants experienced multiple discontinuities throughout the patient journey, most frequently during the transfer from the care of their home community to the regional hospital for birth and back again following hospital admission. The patterns of service use and the quality of a number of aspects of the health services described here will be presented in the following chapter.

# 5 RESULTS

## 5.1 Introduction

As this is a thesis submitted by publication, results appropriate to the research questions are either published, accepted and in press or are currently in submission to a peer-reviewed journal. This chapter contains the publication status of each paper, the specific objectives that the paper endeavoured to answer and the paper itself. A signed statement of the authors' contributions to each paper is in Appendix 14.

**5.2 PAPER 1: Bar-Zeev S, Barclay L, Kruske S, Bar-Zeev N, Yu G, Kildea S.**

**Use of Maternal Health Services by Remote Dwelling Aboriginal Women in Northern Australia and Their Disease Burden.**  
*Birth: Issues In Perinatal Care 2013*

**Paper status:** Accepted, in press

**Research objectives addressed in this paper:**

- To describe the patterns of health service utilisation by Aboriginal mothers at the RHC and the regional hospital during pregnancy, birth and postpartum.
- To document the state of health among Aboriginal women during their pregnancy, birth and the postpartum period.

## **Abstract**

**Background:** Disparities exist in pregnancy and birth outcomes between Australian Aboriginal women and their non-Aboriginal counterparts. Understanding patterns of health service use by Aboriginal women is critical. This study describes the use of maternal health services by remote dwelling Aboriginal women in northern Australia during pregnancy, birth and the postpartum period and their burden of disease.

**Methods:** A retrospective cohort study of maternity care for all 412 maternity cases from two remote Aboriginal communities in the Northern Territory of Australia, 2004–2006. Primary endpoints were the number and type of maternal health related complications and service episodes at the health centres and regional hospital during pregnancy, birth and the first six months postpartum.

**Results:** Ninety-three per cent of women attended antenatal care. This often commenced late in pregnancy. High levels of complications were identified and 23% of all women required antenatal hospitalisation. Birth occurred within the regional hospital for 90% of women. By six months postpartum, 45% of women had documented postnatal morbidities and 8% required hospital admission. The majority of women accessed remote health services at least once, however only one third had a record of postnatal care within two months of giving birth.

**Conclusion:** Maternal health outcomes were poor despite frequent service use throughout pregnancy, birth and the first six months postpartum, suggesting a quality of care rather than access issue. These findings reflect outcomes that are more aligned with the developing rather than developed world and have significant implications for future planning of maternity services that must be urgently addressed.

**Keywords:** Australian, Aboriginal, maternal, service use

## Background

Australia is a wealthy developed country and considered to be one of the safest in the world to give birth [1]. Despite this, there are extraordinary disparities in pregnancy and birth outcomes between Aboriginal and Torres Strait Islander women and other Australian women, reflected in the higher rates of preterm birth (13.3% vs. 8.0%), low birth weight (12.4% vs. 5.9%), perinatal death (17.3 vs. 9.7 per 1000 births) [2] and the maternal mortality ratio (21.5 vs. 7.9 per 100,000 live births) [3] which is known to be an underestimate [4].

Improving outcomes is largely dependent upon improving the social determinants of health [5]; however, health services can also contribute through the provision of timely and effective maternity care [6]. Maternity services delivered by a skilled care provider during pregnancy, birth and the postpartum period can reduce maternal and neonatal mortality and morbidity [7]. This is particularly true in areas where women's health status is poor [8]. The determinants of maternal health service use vary across cultures and are dependent upon individual and household factors, such as economic status, maternal age, level of formal education and place of residence, although many studies have not found consistent patterns of relationships between service use and these individual predictors [9].

In Australia, access and use of health services by Aboriginal people is poorer compared with other Australians. The reasons for these differences include geographical distance to services, cost, language barriers and a lack of culturally appropriate services [10]. Data describing maternal health service access and use by Aboriginal women are limited and require further research [11]. Available data suggests Aboriginal women are less likely to attend mainstream health services, commence antenatal care later in pregnancy and attend for fewer visits compared with non-Indigenous women [12-14]. Planning of maternity services must be informed by an understanding of service use patterns, particularly at the primary level. We therefore aimed to investigate these patterns in a cohort of Aboriginal women from two large remote Northern Territory communities during pregnancy, birth and the postpartum period.

Ethical approval for this study was obtained from the Human Research Ethics Committee of the Menzies School of Health Research and the Northern Territory

Department of Health. This study was part of the larger five-year, National Health and Medical Research Council-funded '*1+1 = A Healthy Start to Life*' study and supported by the remote Aboriginal community health boards and Aboriginal women themselves.

## **Methods**

### **Setting**

The Northern Territory is a vast region of Australia, spanning 1.35 million square kilometres yet has only 1% of the population [15]. One third of the population is Aboriginal or Torres Strait Islander and 81% of these people live in remote or very remote communities [16], ranging in size from a single family to a few thousand people [17]. Health services are provided across the region by the Northern Territory government (Department of Health formerly known as Territory Health Services), Aboriginal community controlled and joint nationally funded services (Figure 6).

The study sites were the health centres in two large (population 2200–2600) purposively-selected remote Aboriginal communities located in the tropical 'Top End' region of the Northern Territory. Most people in these communities experience poverty and live in overcrowded and poorly maintained houses [17]. Access to adequate sanitation and water supply is not the same as in larger regional centres and nutritious, affordable food is limited [18]. There are local councils, shops and schools in both communities. Tradition, culture and local languages are strong. There are regular air services to and from the regional city and road access during the dry season.

Each community has a government-operated health centre with no inpatient beds. Maternity care is provided to at least 100 women per year predominantly by one or two midwives and at times Aboriginal Health Workers, with a full-time onsite doctor who is consulted on referral. An 'outreach' visiting obstetrician and midwife provide additional clinical support several times each year. More complex pregnancy care is managed in the urban centre, Darwin at the regional hospital. This hospital is located approximately 500 kilometres from the communities and is the only major public hospital servicing these areas. It provides comprehensive tertiary maternity, paediatric and newborn care.

Pregnant women requiring hospitalisation are evacuated from the community to Darwin, an approximately one-hour flight by a light fixed wing aircraft.



### TERRITORY HEALTH SERVICES OUTLETS IN THE NORTHERN TERRITORY

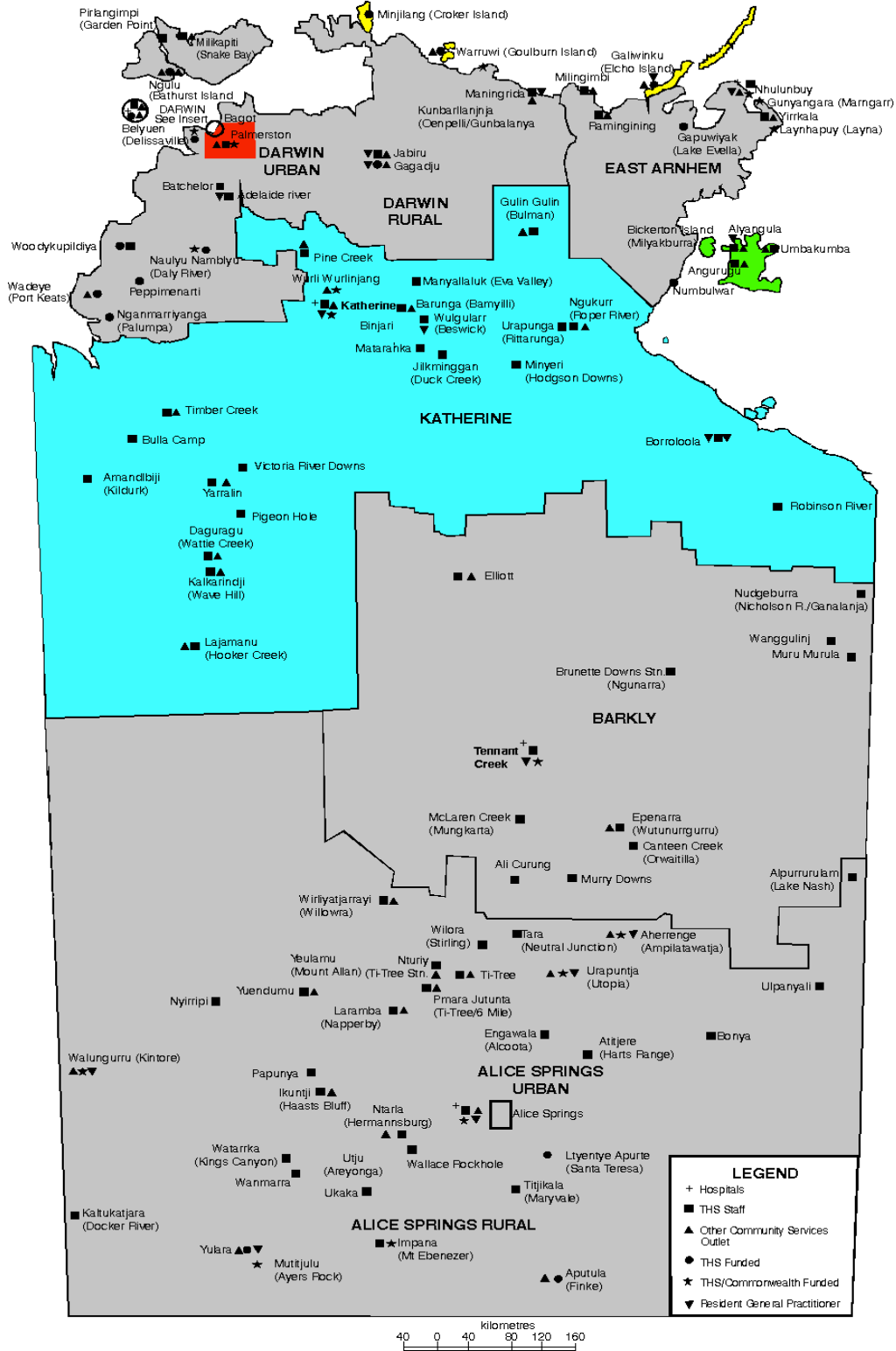


Figure 6: Health services in the Northern Territory

Retention and recruitment of staff in remote communities is difficult [19]. Staff have reported being poorly prepared for their role; receiving inadequate orientation to the health service and limited cultural awareness training [20].

In the Northern Territory, remote dwelling women are transferred from their home community to a regional centre at around 36–38 weeks gestation for the remainder of their antenatal care and hospital birth [21]. Transferred women reside in hostel accommodation until the onset of labour. At the time of the study, women gave birth in hospital with unknown care providers [22]. Women lack social supports during this period as the personal cost of transporting family members is not subsidised by government and prohibitive for families on some of the lowest mean incomes in Australia [23]. Following brief initial postnatal care in hospital, women are transferred back to their home community where postnatal care can be provided by the health centre staff.

### **Design and data collection**

We conducted a retrospective cohort study of Aboriginal women from the two communities who gave birth to an infant with a gestation of at least 20 weeks or birth weight of at least 400 grams, from 1 January 2004 to 31 December 2006 at the regional hospital, in transit to hospital, in their resident community or a hostel. Women were followed up to twelve months postpartum. The cohort was constructed through manual data linkage between community birth records from two remote health centres and medical records at the regional hospital.

Data outlined in Table 3, were collected using manual review of medical records at the hospital and health centres by a researcher with midwifery and child health qualifications.

**Table 3: Maternal data collection**

| <b>Category</b>     | <b>Data collected</b>  |
|---------------------|--|
| <b>Demographics</b> | Age, community of residence, employment, partner status  |
| <b>Antenatal</b>    | Gravida, parity, estimated date of birth<br>Past obstetric history<br><i>Use of antenatal care:</i> <ul style="list-style-type: none"> <li>• Number and location of antenatal visits</li> <li>• Pre-existing medical complications</li> <li>• Pregnancy related complications</li> </ul> <i>Antenatal hospital admissions:</i> <ul style="list-style-type: none"> <li>• Gestation and reason for admission, admission and discharge dates</li> </ul> |
| <b>Birth</b>        | Place of birth<br>Labour and birth outcomes<br>Length of hospital stay   |
| <b>Postpartum</b>   | Postpartum complications<br><i>Postpartum hospital admissions:</i> <ul style="list-style-type: none"> <li>• Reason for admission, admission and discharge dates</li> </ul> <i>Use of remote health services:</i> <ul style="list-style-type: none"> <li>• Date of 1<sup>st</sup> health centre visit following birth, reason for visit</li> <li>• Date of postnatal check</li> <li>• Maternal death</li> </ul>                                       |

Four hundred and twenty women were identified as eligible for the study. Of these women, eight had no community or hospital record. The final cohort consisted of 412 women.

### **Analysis**

Data were entered into an Access™ (Microsoft Corporation) database then cleaned and analysed using STATA™ 11.1 (Statcorp, College Station, Texas) (24). Continuous data are reported as means (95% Confidence Interval (CI)) or medians (Interquartile Range

(IQR)) and compared using 2-tailed t-test assuming unequal variances if appropriate. Dichotomous data are reported as proportions.

Primary endpoints were the number and type of maternal health related complications, the number of maternal service episodes at the health centre and the hospital and hospital admissions during pregnancy, for birth and the first six months postpartum. Hospital admissions were categorised by discharge diagnoses from the discharge summary or the medical record if the summary was not available. Multiple reasons for each admission were recorded.

The period of observation of each woman was from the first presentation during pregnancy until twelve months after giving birth, or the date that the woman died if this occurred first.

## **Results**

Over half of the women in this study were multiparous (57%) with a mean age of 23 years (SD 6.0, CI 22.5–23.7, range 13–41). Of the multiparous and grand multiparous women, one quarter had a previous preterm birth or caesarean section (Table 4).

### **Use of antenatal services**

Ninety-three per cent of women had at least one recorded antenatal visit (Table 5). Of the women who had no antenatal care, no statistical inference could be drawn for age or parity. Mean gestation at birth for 28 women with no record of antenatal care was 34.8 weeks (95% CI 31.8–37.8) weeks and for 384 women with at least one visit was 37.5 weeks (95% CI 37.3–37.8), unequal variance t-test  $p=0.07$ .

**Table 4: Characteristics of women aged 13–41**

| <b>Maternal characteristics</b>        | <b>Total (%) and mean</b>     |
|--|-------------------------------|
| <b>Parity</b>                          | <b>(n=412)</b>                |
| Primiparous                            | 135 (33%)                     |
| Multiparous                            | 234 (57%)                     |
| Grand multiparous                      | 43 (10%)                      |
| <b>Gravida</b>                         | Mean 2.9 (SD 1.9, CI 2.7–3.1) |
| <b>Relationship status</b>             | <b>(n=412)</b>                |
| Married or partner                     | 115 (28%)                     |
| Single                                 | 226 (55%)                     |
| Not recorded                           | 71 (17%)                      |
| <b>Employment</b>                      | <b>(n=412)</b>                |
| Home duties                            | 194 (47%)                     |
| Unemployed                             | 50 (12%)                      |
| Student                                | 50 (12%)                      |
| Employed                               | 45 (11%)                      |
| Not recorded                           | 73 (18%)                      |
| <b>Previous obstetric history</b>      | <b>(n=277)</b>                |
| Previous preterm birth                 | 68 (25%)                      |
| Previous caesarean section             | 70 (25%)                      |
| Previous vaginal birth after caesarean | 27 (10%)                      |
| Previous stillbirth                    | 15 (5%)                       |
| Previous neonatal death                | 7 (3%)                        |

**Table 5: Number of antenatal visits**

| <b>Number of antenatal visits</b> | <b>Total (%)</b> |
|-----------------------------------|------------------|
| 0 visits                          | 14 (3%)          |
| 1–3 visits                        | 40 (10%)         |
| 4–6 visits                        | 81 (20%)         |
| 7–10 visits                       | 126 (31%)        |
| 11+ visits                        | 137 (33%)        |
| Not recorded                      | 14 (3%)          |

Thirty-nine per cent of women presented for antenatal care in the 1<sup>st</sup> trimester, with most women presenting for the first time in the second trimester (51%) at 16.7 weeks (95% CI 15.8–17.6, SD 8.8) with an average of 9 visits (95% CI 8.4–9.4, 0–29 range, median 8, IQR 5–12, SD 5.2) occurring through the pregnancy. Once antenatal care commenced, visits were frequent and occurred every 3 weeks until birth. Most antenatal care (81%) was provided at the health centre, with the remaining visits occurring at the regional hospital.

### **Medical complications**

Thirty-four per cent of all women had pre-existing medical comorbidities (n=143). The most frequently recorded were cardiac related complications (including pre-existing hypertension and rheumatic heart disease) (16%), diabetes (6%), asthma (6%) and autoimmune disorders (6%).

Among the women who received antenatal care and routine screening, the most prevalent complications identified were anaemia (<11.0g/dL) (50%), abnormal urine test results indicating a urinary tract infection (45%) and sexually transmitted infections (22%). Twenty-one per cent of all women had an actual preterm labour resulting in preterm birth.

### **Antenatal hospital admission**

Twenty-three per cent of women (n=96) required hospital admission at least once during pregnancy (mean 0.29, range 0–6). The mean gestation on admission was 30.6 weeks (SD 8.4, range 5–41 weeks) and median length of stay was 3 days (IQR 2–4). Pregnancy related admissions diagnoses were primarily related to preterm labour (both threatened and actual preterm labour) (23%) and early labour at term (13%) (Table 6).

**Table 6: Per cent and number of antenatal hospital diagnoses**

| <b>Diagnoses for antenatal admission</b>                                 | <b>Total (n=120 diagnoses) (%)</b> |
|--|------------------------------------|
| Preterm labour ( <i>9 preterm labour, 19 threatened preterm labour</i> ) | 28 (23%)                           |
| Early labour   | 15 (13%)                           |
| Gestational hypertension   | 7(6%)                              |
| Hyperemesis  | 8 (6%)                             |
| Prelabour rupture of membranes   | 6 (5%)                             |
| Antepartum haemorrhage   | 5 (4%)                             |
| Preeclampsia   | 5 (4%)                             |
| Urinary tract infections   | 5 (4%)                             |
| Oligohydramnios  | 4 (3%)                             |
| Preterm rupture of membranes   | 4(3%)                              |
| Placenta previa  | 3 (2.5%)                           |
| Management of gestational diabetes                                       | 3 (2.5%)                           |
| Cardiac  | 3 (2.5%)                           |
| Other (surgical/other medical illness)                                   | 25 (21%)                           |

## **Birth**

The majority of women (90%) gave birth at the regional hospital (inborn). Median length of hospital stay for all women was 4 days (IQR 3–6, range 1–38). Among the inborn infants (n=371), 19% were preterm. Mean gestation for inborns was 37.6 weeks (SD 2.6, 95% CI 37.3–37.9) and mean birth weight was 2998g (SD 629, 95% CI 2933–3062).

Ten per cent of births occurred outside of the hospital (n=42), predominantly in the remote community (outborn). Of these births (n=15), 36% were preterm. Mean gestation for outborns was 36.2 weeks (SD 3.6, 95% CI 35.0–37.2); p=0.001 and birth weight 2726gm (SD 837, 95% CI 2477–2974); p=0.008. Gestational age distribution for all births is reported in Table 7. Most women, regardless of place of birth, had a non-instrumental vaginal birth (69%).

**Table 7: Gestational age at birth for 413 infants**

| <b>Gestation at birth (in weeks)</b> | <b>n=413 (%)</b>    |
|--------------------------------------|---------------------|
| 20–27 weeks                          | 8 (2%)              |
| 28–31 weeks                          | 14 (3%)             |
| 32–34 weeks                          | 20 (5%)             |
| 35–36                                | 43 (10%)            |
| 37+ weeks                            | 328 (79%)           |
| Mean gestation (all infants)         | 37.4 weeks (SD 2.9) |

### **Postpartum**

Primary postpartum haemorrhage (classified in this study as a blood loss of 500mL or more for vaginal birth or 750mL or more for a caesarean section) occurred in 21% of all births; 5% of all women had a postpartum haemorrhage estimated to be greater than 1000mL. Of the women who birthed outside of hospital, 77% were admitted within 72 hours following birth, predominantly for preterm birth, other infant medical reasons, and postpartum haemorrhage.

One third of all infants required admission to the neonatal nursery at the regional hospital, mainly for preterm birth and low birth weight. Fifteen per cent of women admitted to hospital were discharged without their infants, as they required ongoing neonatal nursery care. Contraception was provided to 12% of women prior to hospital discharge, most commonly Implanon (51%), Depo-Provera (28%) and tubal ligation (13%).

By 6 months postpartum 45% of all women had documented morbidities (Table 8). Following postpartum haemorrhage, anaemia was the most frequent postpartum diagnosis (20%) with 22% of the anaemic women requiring a blood transfusion. Infections of the reproductive tract and urinary tract infections were identified in 8% of the women.



**Table 8: Morbidities recorded among all women within the first six months postpartum**

| <b>Morbidities</b>  | <b>Total (%)</b> |
|---|------------------|
| Primary postpartum haemorrhage  | 85 (21%)         |
| Secondary postpartum haemorrhage  | 2 (<1%)          |
| Anaemia – Hb <110gm/dL (all)  | 83 (20%)         |
| <i>Anaemia requiring a blood transfusion</i>  | 18/83 (22%)      |
| Reproductive tract infections ( <i>including puerperal fever, postpartum sepsis, caesarean section wound infection, endometritis, uterine infection, perineal or genital tract infections</i> ) | 35 (8%)          |
| Urinary tract infection   | 32 (8%)          |
| Breast infection  | 12 (3%)          |
| Breast feeding attachment difficulties/supply issues  | 14 (3%)          |
| Respiratory infection   | 14 (3%)          |
| Hypertension  | 9 (2%)           |
| Mental health issues ( <i>including postnatal depression, postpartum psychosis and attempted suicide</i> )  | 8 (2%)           |
| Pelvic pain or instability  | 2 (<1%)          |
| Venous thrombosis   | 2 (<1%)          |

### **Remote health service use**

Sixty-four per cent of women accessed the remote health centre during the first six months following birth, typically within the first two months postpartum. Acute medical conditions and follow-up examinations, tests or treatment for pre-existing medical conditions were the leading reasons for first presentations (49%); followed by routine postnatal care (41%) and contraception (6%). Just over one third (33%) of women had documented postnatal care at the remote health centre by eight weeks postpartum.

### **Postpartum hospital admission**

Eight per cent of all women were admitted to hospital at least once within six months postpartum. More than half of the admissions were for the establishment of lactation following infant discharge from the neonatal nursery (51%). Acute illness (mainly

respiratory infections) and surgery (28%), breast infections or other breastfeeding problems (9%) and endometritis (9%) were among the other leading reasons for admission. Median length of stay was two days (IQR 1–5, mean 3.4, SD 3.0, range 1–12). No maternal deaths were recorded in this study.

## **Discussion**

This study reports previously undocumented patterns of maternal health service use from pregnancy through to the postpartum period by Aboriginal women from two of the biggest remote communities in northern Australia.

We described very high rates of health service use at the primary and referral level, reflecting the willingness by women to access services, despite barriers previously described [10]. It also reveals an unacceptable burden of disease in this population with high rates of pre-existing medical and pregnancy related complications and antenatal hospitalisations. Anaemia, urinary tract infections and preterm birth were among the most common pregnancy related complications identified. All had prevalence rates consistent with those reported in many developing countries [25-27] and have avoidable factors that should be addressed with quality care.

Most (78%) non-Indigenous Australian women attend for antenatal care in the first trimester compared to 39% of the Aboriginal women in this population [28]. Whilst the women in this study commenced antenatal care later in pregnancy, the average number of visits attended was within the range recommended by the World Health Organization [29]. However, despite regular attendance for antenatal care, outcomes such as preterm birth (21%) remained very high. This questions the effectiveness and quality of the antenatal care provided and is currently being investigated by the authors. Staffing for maternal health services in health centres during the period of data collection was not determined by the burden of disease or patterns of service use and appears insufficient to meet the needs of the population. The high workload identified in remote health services is compounded by staffing shortages and rapid turnover resulting in repeated training of new staff [20].

Almost one quarter of women required antenatal hospital admission. One of the leading reasons for admission was early labour at term. There was no national comparative data available for this. During our data collection period, few women from these

communities had social supports or a known support person during labour and birth. This may explain the high admission rate. As a result of the findings from this study and the larger study, combined with increased funding from the national government aimed at 'Closing the Gap' between the health outcomes for Aboriginal and non-Aboriginal Australians [30] a continuity of care model (Midwifery Group Practice) was implemented for remote dwelling Aboriginal women in 2009. This model of care includes labour support by an Aboriginal Elder, Aboriginal student midwives and other known midwives, in the hostel accommodation and in hospital for birth. Evaluation of this model of care by the authors has shown many improvements to quality of care and maternal and infant outcomes [31]. This is currently being prepared for publication.

Most births were in the regional hospital, although 10% (42/412) occurred outside the hospital, consistent with other research (22, 32-33). This is higher than the previously reported out-of- a description of the way health services at the health centre and referral level were accessed and used by mothers and infants from the two remote communities in this study hospital birth rate for non-Aboriginal women of 0.9% (2629/294,540) (34) and represents a risk ratio of 11.4 (95% CI 8.6-15.2,  $p < 0.01$ ). A related study identified that many of these women who gave birth in their remote communities chose to do so because of prior negative experiences with mainstream hospital services [32].

Following birth, postpartum haemorrhage is experienced by 5-15% of women in high-income countries, such as Australia [35]. It is also one of the leading causes of maternal morbidity and mortality in developing countries [36]. One fifth of all women had a documented primary postpartum haemorrhage in this study, despite the overwhelming majority of births being attended to by skilled maternity care providers in well-resourced health facilities. There has been a recent rise in the proportion of Australian women experiencing postpartum haemorrhage [35, 37] and requiring interventions such as blood transfusions [38]. This increase is thought to relate to inadequate management of the third stage of labour and observation during the immediate postpartum period [35, 37-38]. The reason for the high prevalence of postpartum haemorrhage in this population has not been previously reported and warrants further critical investigation.

Health centres were used by the majority of women postnatally although most first visits to the health centre following birth were for acute illness or treatment for pre-existing conditions and not routine postpartum care as would have been expected. The provision of postnatal care by remote health services was poor, with many women having no documented postnatal care. Poor communication between the hospital and the health centres has resulted in women with medical complications, such as mastitis or wound infections, being discharged without appropriate follow up in their community [39]. These health centres largely rely on women self-presenting for postnatal care and do not routinely offer postnatal home visits, unlike other models of care available to the majority of women living in urban and regional areas of Australia [40]. This seriously disadvantages these women and could result in delays to health care seeking until a serious complication develops and may explain the high prevalence of maternal morbidity.

Some strategies aiming to improve outcomes of Australian Aboriginal mothers and infants have been recently implemented. Despite a lack of robust evidence [41], a number of key factors contribute to their success such as providing services that are flexible, community-based, include home visiting and continuity of care, and are integrated with other services, such as the hospital. There is also a need to have Aboriginal and non-Indigenous workers providing care in partnership [42]. Most of these factors were lacking in the health services investigated in this study. Aboriginal Health Workers and other community-based workers are ideally positioned to provide antenatal or early postnatal care in a culturally safe framework using a community development approach. This could potentially reduce the workload for health centre-based clinicians. However this seldom occurs in many remote settings.

For the past three decades numerous maternity service reviews and consultations with Aboriginal and Torres Strait Islander women in the Northern Territory have emphasised the lack of culturally responsive health services, absence of continuity of care in service delivery and poor service coordination and communication between health care providers [21, 22, 43-46], yet there has been little change in pregnancy and birth outcomes or improvement to health services for remote dwelling Aboriginal women in Australia.

Over the past few years however, since our collection of data reported here, there have been substantial changes made to respond to these issues and improve maternity services. This seems to be occurring through a coordinated evidence-based strategy for maternity services. This has been addressed through the implementation of designated midwife position across a small number of remote communities enabling a midwifery service to operate five days a week and on call after hours with back up from the other nurse-midwives when required. This frees up the 'outreach' midwifery services that are based in the regional centre to concentrate their services on increasing the number of visits to communities where there is no onsite skilled maternity care provider. However, without midwives being a minimum staffing criteria for these communities there have already been times when the designated midwife has not been replaced for holiday relief leaving large remote communities with arguably the greatest need in Australia, without onsite midwives.

The Midwifery Group Practice described previously, is a further innovation, that aims to improve the continuity and quality of care, and increase support for remote dwelling women relocated from their home community to the regional centre for birth [31].

Many of the complications described in this study are potentially avoidable with targeted interventions. However it is clear that a different approach is required. There is still an urgent need to further improve the way maternity services are organised and delivered in all remote communities to ensure women are receiving high quality care by an appropriately skilled health workforce in a culturally appropriate model.

The return of birthing services within a community development approach, as seen with remote Inuit maternity models, has shown extraordinary improvements to maternal and infant health outcomes despite vast distance from tertiary services [47]. This has been requested by Aboriginal women themselves [48] and must also be explored, particularly as the previous model has been unsuccessful in achieving high quality care and maternal and infant outcomes [20].

### **Limitations**

During the antenatal period, we only recorded health service presentations that specifically included antenatal care. This may underestimate the overall rate of service utilisation as other non-pregnancy related presentations were excluded. This study also

does not take account for the service use by pregnant women who miscarried or had a termination at less than 20 weeks gestation. Also given the mobility of Aboriginal people across the Northern Territory [49], it is possible that women presented for antenatal or postnatal care at other health services or were admitted to a hospital other than the regional hospital reviewed in this study. In this case our results of service utilisation may be an underestimation.

## **Conclusion**

Remote dwelling Aboriginal women frequently use maternal health services at the primary and referral level commencing in pregnancy and continuing through the postpartum period. This reflects willingness by Aboriginal women to access health services and also highlights the serious disease burden and poor maternal and infant health outcomes in this population. An insufficient number of staff are available to deal with high workloads as a result of these patterns of use and severity of presentations. Progress towards addressing the serious inequities in care delivery and improving outcomes for these women and their infants is being made but the organisation of services, effective use of staff and quality of care at the primary and referral levels, must be targeted by health care planners.

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### **5.3 PAPER 2: Bar-Zeev S, Barclay L, Kruske S, Kildea S.**

**Factors Affecting the Quality of Antenatal Care Provided to Remote Dwelling Aboriginal Women in Northern Australia. *Midwifery* 2013**

**Paper status:** In press

#### **Research objectives addressed in this paper:**

- To measure clinicians' adherence to local guidelines for antenatal care and the follow up of identified problems, as a measure of the quality of care.
- To identify the barriers to quality health service delivery for Aboriginal mothers.

## **Abstract**

**Objective:** There is a significant gap in pregnancy and birth outcomes for Australian Aboriginal and Torres Strait Islander women compared with other Australian women. The provision of appropriate and high quality antenatal care is one way of reducing these disparities. The aim of this study was to assess adherence to antenatal guidelines by clinicians and identify factors affecting the quality of antenatal care delivery to remote dwelling Aboriginal women.

**Setting and design:** A mixed method study drew data from 27 semi-structured interviews with clinicians and a retrospective cohort study of Aboriginal women from two remote communities in Northern Australia, who gave birth from 2004–2006 (n=412). Medical records from remote health centres and the regional hospital were audited.

**Measurements and findings:** The majority of women attended antenatal care and adherence to some routine antenatal screening guidelines was high. There was poor adherence to local guidelines for follow up of highly prevalent problems including anaemia, smoking, urinary tract infections and sexually transmitted infections. Multiple factors influenced the quality of antenatal care.

**Key conclusions and implications for practice:** The resourcing and organisation of health services and the beliefs, attitudes and practices of clinicians were the major factors affecting the quality of care. There is an urgent need to address the identified issues in order to achieve equity in women's access to high quality antenatal care with the aim of closing the gap in maternal and neonatal health outcomes.

**Keywords:** Aboriginal, antenatal care, remote, quality

## Introduction

In Australia, Aboriginal and Torres Strait Islander women represent 4% (11,792) of all women who give birth (294,814) [1]. Fifty-two per cent of these women live in outer regional and remote areas [2]. Compared with non-Aboriginal women, there is a significant difference in pregnancy and birth outcomes. Teenage pregnancy, smoking in pregnancy, gestational diabetes and hypertensive disorders are more prevalent [3] and the maternal mortality ratio is more than two and a half times higher among Aboriginal women and known to be underestimated [4]. The perinatal death rate is twice as high for Aboriginal babies relative to other non-Indigenous babies (17.3 per 1000 birth vs. 9.7), as is preterm birth (13.3% vs. 8.0%) and low birth weight (12.4% vs. 5.9%) [2].

A complex range of factors contributes to these disparities. These factors include less access to culturally secure health services, sustained institutional racism, lower educational attainment and poverty, a higher burden of disease that commences early in life and the continuing effects of colonisation [5-6].

Antenatal care (ANC) provides an opportunity to improve the health of the mother and her infant [7]. In Australian Aboriginal communities numerous factors have been identified to improve ANC attendance, care provision and birth outcomes. These include: continuity of carer, an appropriately skilled workforce, integration with other services (such as the hospital), outreach activities, flexibility in care delivery and respect for culture and family involvement in health issues and community-based or community-controlled services whereby people in the Aboriginal community initiate and operate health care services to deliver comprehensive and culturally appropriate services to their own community members [8-12].

Across the country ANC is typically provided by midwives and doctors, not all of whom have obstetric qualifications. In rural and remote areas registered nurses who do not necessarily have midwifery skills also provide this care [6]. There is a known shortage of registered nurses with midwifery and child health qualifications in remote Australia. In these settings the number of registered nurses with these qualifications declined from 65% and 18% respectively in 1995 to 29% and 11% in 2008 [13]. Retention of staff in remote areas is also difficult [14].

Aboriginal women commence ANC later during pregnancy and have fewer visits compared with non-Indigenous women [15-16]. Utilisation of ANC itself does not always ensure quality of service provision. There is limited data regarding the quality of ANC delivered to remote dwelling Aboriginal women [15-17] and the factors that influence the delivery of this care.

The data presented here is from a baseline study nested within the '*1+1 = A Healthy Start to Life*' project which aimed to improve maternal and infant health for remote dwelling Aboriginal families in the Top End of the Northern Territory (NT). It used a participatory approach to a mixed methods design with baseline data informing interventions. The project was developed in response to long standing concerns voiced by Aboriginal women, policy makers and health providers about the quality of maternity services and culturally unsafe practices [18-22]. Here we describe the quality of ANC delivery, the service gaps and barriers to care.

## **Methods**

### **Setting**

The study sites were the health centres (HCs) in two of the largest remote Aboriginal communities (population 2200–2600) in the tropical Top End of Australia's NT, located approximately 500km from the regional centre, Darwin. The third study site, the regional hospital in Darwin, is the main public hospital servicing these communities and provides tertiary-level care including maternity, newborn and paediatric care.

Antenatal care in these remote communities is generally provided at government HCs by core local staff and includes clinical support from visiting specialists. The Women's Business Manual (WBM 3<sup>rd</sup> edition) [23] provides standard screening and management guidelines for ANC and is used by clinicians working in these settings. More complex pregnancy care and specialist tests are managed at the regional hospital. Women are generally transferred to the regional centre at 36–38 weeks gestation where they have the remainder of their ANC and give birth in hospital [24].

Following community consultation and endorsement approval for this study was obtained from the NT Department of Health and Families (DHF), local health boards and Community Councils and the Human Research Ethics Committee of the Menzies School

of Health Research. Written consent was obtained from interview participants prior to interviews.

## **Design**

A mixed method design [25] was used in this study. Qualitative and quantitative data were collected and analysed to inform health service improvements and report the views of the range of staff involved in the provision of ANC within the HCs and hospital. Data collection occurred from January to August 2008.

### ***Retrospective cohort study***

We conducted a retrospective cohort study of Aboriginal mothers from these two communities who gave birth from 2004–2006. All Aboriginal women who gave birth to an infant at the regional hospital, in hostel accommodation, in transit to regional hospital or in the remote community from 1<sup>st</sup> January 2004 to 31<sup>st</sup> December 2006 with gestation of at least 20 weeks or birth weight of at least 400 grams, were eligible for inclusion in the study.

The study cohort was constructed through manual data linkage between community birth records from the HCs and medical records at the regional hospital. Four hundred and twenty women were identified as eligible for the study. Eight women had no available record at either the hospital or HC. The final cohort consisted of 412 women.

Quality of antenatal health care delivery was assessed using manual review of medical records at the hospital (n=412) and HCs (n=399). All women should have their antenatal medical records copied and transferred from the remote health centre to the regional hospital but at times this did not occur.

The main outcome measures included attendance at ANC and the adherence to recommended WBM antenatal guidelines [23] for routine ANC, screening tests and follow up of identified health conditions. Adherence to selected guidelines for smoking in pregnancy, genetic screening for foetal anomalies, anaemia, sexually transmitted infections (STIs), urinary tract infections (UTIs) and Group B streptococcus (GBS) were examined in detail given the high prevalence of these conditions among Aboriginal women and good evidence that exists for their screening and treatment during pregnancy.



## Interview data

The first author conducted 27 semi-structured interviews with key clinicians involved in the provision of ANC in the HCs (n=19) and at the hospital (n=8) (Table 9). Purposive sampling was used to identify and recruit the first nineteen participants. Snowball sampling was used to recruit the remaining participants, as we required expert clinicians who worked in specific roles. Often these clinicians were unknown to the authors and therefore hard to identify. Recruitment continued until data saturation had been reached in the analysis. Interviews included questions about the clinicians' role in the provision of ANC and the barriers to providing this care for remote dwelling Aboriginal women.

**Table 9: Interview participants**

| <b>Location</b>         | <b>Health Staff (n=27)</b>  |
|-------------------------|---|
| HC 1 (n=10)             | District Medical Officers (n=2)<br>Remote Area Nurses (n=2)<br>Midwives (n=3)<br>Aboriginal Health Worker (n=1)<br>Clinical service managers (n=2)  |
| HC 2 (n=9)              | District Medical Officers (n=2)<br>Remote Area Nurses (n=2)<br>Midwives (n=2)<br>Aboriginal Health Workers (n=1)<br>Clinical service managers (n=2) |
| Regional Hospital (n=8) | Outreach (visiting) midwives (n=4)<br>Obstetric doctors (n=2)<br>Clinical service managers (n=2)  |

## Data analysis

Medical record data were entered into an Access™ (Microsoft Corporation) database and cleaned and analysed descriptively using STATA™ 10.1 (Statcorp, College Station, Texas). Interviews were tape recorded with the participant's consent and transcribed

*verbatim*. Pseudonyms were used to preserve anonymity. The transcribed material was analysed by the first author (SBZ) under supervision of author LB using content analysis in ATLAS™ T.I 5.4 (Scientific Software Development GmbH, Berlin, Germany). The transcriptions were examined by the first author to identify issues and themes in the data and codes were assigned to units of meaning apparent in each paragraph or sentence. Data were then merged into higher-level categories and core themes selected. Frequencies of responses within the core themes were subsequently identified. Qualitative and quantitative data sources were used to corroborate our findings around the issue of the quality of care received by women during the antenatal period.

## **Results**

Antenatal care findings were documented either on the antenatal record or within the patient's medical record in the HC or hospital. Where documentation of routine care and follow up of identified problems according to the WBM guidelines was absent, it was assumed that the activity, i.e. STI screening, did not take place.

Ninety-three per cent of women (n=384) had a record of at least one antenatal visit during pregnancy at either the regional hospital or HC with a mean of 9 visits (CI 8.4–9.4, range 0–29). The 1<sup>st</sup> visit typically took place in the second trimester (mean gestation 16.7 weeks; CI 15.8–17.6, SD 8.8). The median age for women attending their 1<sup>st</sup> visit was 23.3 years (range 13–41) and most women (57%) were multiparous.

At the first antenatal visit (Table 10) most women who presented before 12 weeks had a record of being prescribed folate. Recording of routine blood tests at the 1<sup>st</sup> visit was high with the uptake of individual tests varying between 81–91%. Documentation of routine care including urinalysis, mid-stream urine (MSU) tests and blood pressure (BP) was generally high (range 82–85%).

Documentation of foetal anomaly screening was absent for the majority of women. Only 9% of women who presented before 20 weeks were offered maternal serum screening and less than half of the women accepted this screening test when offered. Most women (92%) had a record of at least one ultrasound (mean 1.5, range 1–4) undertaken at a mean gestation of 20.2 weeks (SD 7.8).

Smoking status and cessation advice were poorly recorded. There was no record of smoking status for 41% of women at the 1<sup>st</sup> antenatal visit and close to 90% at the 36 week visit. Smoking was identified among one third of women at the 1<sup>st</sup> visit and 7% at the 36 week visit. Only 8% of these women had a record of smoking cessation advice at the first visit increasing to 61% at the 36 week visit. Alcohol use was very poorly recorded. Forty-five per cent and 90% of women did not have this information recorded at their 1<sup>st</sup> and 36 week visit, respectively.

Documentation of screening for STIs, UTIs and anaemia was generally high (range 83–91%) with the exception of gestational diabetes (61%) and GBS (57%). Follow up for identified problems however, was variable. Most women had at least one full blood examination (FBE) during pregnancy and anaemia prevalence (Hb <110gm/dL) was 50%. One quarter of these women had no record of anaemia treatment. Where treatment was delivered according to the guidelines, oral iron was most commonly administered. A follow up FBE or Hb test was recorded for 74% of women. STI prevalence was high with 22% of women having at least one STI (mean 1.3) and treatment was recorded for 83% of STIs.

Documentation of urinalysis testing during antenatal visits was high (86%), with a mean of 7.3 tests per woman. Forty-five per cent of women had at least one positive urinalysis test indicating a UTI and the mean proportion of positive urine tests sent for further investigation (MSU) was 71%; 82% of women with a positive test were given immediate treatment with antibiotics. Just over half of all women had a record of low vaginal (LV) swabs for GBS. Of these, nearly one third of the results were positive; indicating the recommendation for antibiotics in labour; however, around 25% of these women who laboured did not receive antibiotics.

**Table 10: Documented antenatal care**

| <b>1<sup>st</sup> antenatal visit</b>  | <b>% (Total number / denominator)</b> |
|--|---------------------------------------|
| Proportion of women who presented for ANC in the 1 <sup>st</sup> trimester and were prescribed folate        | 75% (118/157)                         |
| <b>Routine blood tests at 1<sup>st</sup> visit</b>   |                                       |
| Blood group/Rhesus   | 91% (350/384)                         |
| Antibodies   | 91% (350/384)                         |
| FBE  | 82% (316/384)                         |
| Hepatitis B surface antigen  | 90% (345/384)                         |
| Syphilis serology  | 91% (348/384)                         |
| Rubella  | 90% (347/384)                         |
| HIV  | 81% (311/384)                         |
| Blood pressure   | 83% (318/384)                         |
| MSU  | 82% (314/384)                         |
| Urinalysis (dipstick)  | 85% (327/384)                         |
| <b>Foetal anomaly screening</b>  |                                       |
| Proportion of women who presented for ANC under 20 weeks gestation and were offered foetal anomaly screening | 9% (22/242)                           |
| First trimester combined screening or maternal serum screening   | 45% (10/22)                           |
| Nuchal translucency scan   | 5% (1/22)                             |
| Amniocentesis  | 5% (1/22)                             |
| <b>Ultrasounds</b>   |                                       |
| Ultrasound in pregnancy  | 92% (354/384)                         |
| Mean number of ultrasounds   | 1.5 (range 1–4)                       |
| Mean gestation at 1 <sup>st</sup> ultrasound   | 20.2 weeks (SD 7.8)                   |
| <b>Cigarette use</b>   |                                       |
| <b>1<sup>st</sup> antenatal visit</b>  |                                       |
| Current cigarette use at 1 <sup>st</sup> visit   | 31% (120/384)                         |
| No cigarette use at 1 <sup>st</sup> visit  | 28% (107/384)                         |
| Cigarette use not recorded /missing data   | 41% (157/384)                         |
| Smoking cessation advice recorded at 1 <sup>st</sup> antenatal visit   | 8% (9/120)                            |
| <b>36 week visit</b>   |                                       |
| Current cigarette use at 36 week visit   | 7% (23/322)                           |
| No cigarette use at 36 week visit  | 5% (15/322)                           |
| Cigarette use not recorded/missing data  | 88% (284/322)                         |

|   |                  |
|---|------------------|
| Smoking cessation advice recorded at 36 week visit                      | 61% (14/23)      |
| <b>Alcohol use</b>  |                  |
| <b>1<sup>st</sup> visit</b>   |                  |
| Current alcohol use at 1 <sup>st</sup> visit                            | 1% (5/384)       |
| No current alcohol use at 1 <sup>st</sup> visit                         | 54% (207/384)    |
| Alcohol use not recorded/missing data                                   | 45% (172/384)    |
| <b>36 week visit</b>  |                  |
| Current alcohol use at 36 week visit                                    | 1% (2/322)       |
| No current alcohol use at 36 week visit                                 | 9% (28/322)      |
| Alcohol use not recorded/missing data                                   | 90% (292/322)    |
| <b>Gestational diabetes tests</b>                                       |                  |
| Glucose challenge test  | 61% (236/384)    |
| Glucose tolerance test  | 22% (86/384)     |
| <b>STIs</b>   |                  |
| STI screening (gonorrhoea, chlamydia, trichomoniasis)                   | 83% (320/384)    |
| At least one STI detected   | 22% (71/320)     |
| Mean number of STIs   | 1.3 (range 1–3)  |
| Documented treatment for all STIs                                       | 83% (59/71)      |
| <b>Anaemia</b>  |                  |
| Hb test or FBE at least once during pregnancy                           | 91% (348/384)    |
| Hb <110g/L  | 50% (174/348)    |
| Mean Hb when anaemia diagnosed  | 100g/L           |
| Mean gestation when anaemia diagnosed                                   | 24 weeks         |
| Iron prescribed   | 75% (131/174)    |
| <b>Iron treatment prescribed</b>  |                  |
| Oral iron supplements   | 77% (101/131)    |
| IM iron   | 16%(21/131)      |
| Combination of IM and oral iron   | 5% (7/131)       |
| Blood transfusion   | <1% (1/131)      |
| Combination of blood transfusion and IM iron                            | <1%(1/131)       |
| Follow up FBE or Hb test  | 74% (97/131)     |
| <b>Urinalysis</b>   |                  |
| Proportion of women who had at least one urinalysis                     | 86% (330/384)    |
| Mean number of urine tests  | 7.3 (range 0–24) |
| Proportion of women who had at least one episode of positive urinalysis | 45% (147/330)    |
| Positive urinalysis results sent for MSU                                | 71% (104/147)    |
| Antibiotics prescribed  | 82% (121/147)    |

| <b>Low vaginal swab for GBS</b>                                    |               |
|--|---------------|
| Low vaginal swab for GBS   | 57% (220/384) |
| Positive result indicating recommendation of antibiotics in labour | 27% (61/220)  |
| Antibiotics given in labour to eligible women who laboured         | 76% (41/54)   |

### **Factors affecting quality of antenatal care delivery**

Among the 27 interview participants most (n=22) believed that ANC was a priority area for improvement and all identified multiple factors affecting the quality of care delivery. The core themes in the data were the organisation of maternal health services, discontinuities in care and lack of service coordination, a lack of cross-cultural knowledge and the beliefs, attitudes and practices of the clinicians.

### **Organisation of maternal health services**

In the remote HCs ANC was predominantly provided by midwives and District Medical Officers (DMOs) within business hours. One HC had a midwife allocated to the antenatal program two days per week and the other 1–2 midwives available five days per week for antenatal and postnatal care though they were also responsible for the women's health program. Participants from both HCs stated the staffing levels were insufficient to provide high quality ANC given the large volume of women using the service, many of whom had multiple pre-existing medical conditions, pregnancy complications and complex family situations. Cultural and linguistic barriers also compounded these issues. Women using antenatal services were predominantly residents of the community however, other women visiting family or friends in the community also accessed services creating an additional and often unacknowledged workload as medical records and patient information needed to be sourced by the health provider from other HCs across the NT or interstate. Despite clinicians raising these workload issues with management participants felt these issues were never adequately addressed and for some, this affected their intention to continue their employment in the HC.

## **Discontinuities in care and lack of service coordination**

Women were generally provided with some continuity of carer at the HC during their pregnancy with a midwife or DMO. Although at times these HCs were short staffed and often experienced a rapid turnover of staff with some staff being employed on 2-week contracts. Continuity was compromised if women presented to the HCs with a non-pregnancy related problem, as a different clinician to the midwife or DMO would often see them. Participants from the HCs stated that follow up of pregnancy related problems such as anaemia were usually seen to be the responsibility of the midwife. Other clinicians often left the management of these problems until the woman returned to the midwife for ANC.

Women experienced discontinuity of carer more frequently at the regional hospital and often saw multiple different clinicians at every antenatal visit. Discontinuities in communication and documentation that arose from multiple, delayed or absent handovers of patient results or antenatal management plans between hospital and HC staff or *vice versa*, contributed to women receiving inadequate care. One participant noted:

*'The fact that the ladies see one doctor for one visit then another for the next visit (at the hospital) often means that stuff doesn't get followed up...they expect that we'll do it out here (in the community) and we expect they'll do it in the hospital...it's crossed wires all the time.'* (KA 1)

## **Cross-cultural knowledge**

More than half of all non-Indigenous participants (n=15) cited their lack of cross-cultural knowledge and communication skills as affecting their ability to provide quality ANC. Two participants were of Aboriginal or Torres Strait Islander descent and two non-Indigenous participants who worked in the HCs spoke an Aboriginal language local to the region where English was a second, third or fourth language to many women. Some non-Indigenous participants stated that their age (if they were young) or limited clinical experience working with pregnant Aboriginal women affected the confidence and trust of the women who attended for ANC.

Most participants (n=20) felt that the antenatal services would benefit from more involvement of Aboriginal staff and believed that much of the routine care, particularly health promotion, would be best provided by Aboriginal staff with clinical input of non-Aboriginal staff as needed. Despite this common view among clinicians, AHWs who were often known to the women and some who had many years of experience working in the communities were seldom involved in clinical care. Instead they were assigned to administrative duties such as the recording of results in patient records or filing.

### **Beliefs, attitudes and practices of clinicians**

Specific antenatal guidelines for clinicians working with Aboriginal women were available across the health services; however participant assumptions and attitudes about the women's cultural beliefs at times determined the type and extent of clinical care that women would receive. This was more evident among remote clinicians than those at the regional hospital or providing outreach services.

Two participants noted:

*'I don't offer them (screening tests for foetal anomalies)...they wouldn't want to have these tests anyway...if something was wrong they wouldn't have an abortion.'* (RS 4)

*'Giving up smoking is not a priority for them (pregnant women).. they live with a bunch of smokers, have a million things happening in their lives...talking about quitting is not very useful, maybe they'll just cut down a bit but not quit.'* (LA 9)

Some participants chose not to follow particular aspects of the local guidelines such as discussing drug and alcohol use, despite this being part of their clinical role. They were concerned that it would potentially threaten their ongoing relationship with the women and that women may not return for future care if they felt they were being judged or blamed for particular behaviours:

*'Domestic violence, grog (alcohol) use and smoking are real big problems.. but we (non-Aboriginal midwives) can't be the one trying to talk to them (pregnant women) about this...it needs to be health workers, the old ladies (Elders) doing all the talking...I feel like it always comes across like you're shaming (embarrassing, humiliating) them if you bring it up...like pointing fingers.'* (KM 7)



Nearly half of all participants (n=13) stated women often present late or infrequently for ANC because of family commitments, lack of transport or the perceived lack of benefit in attending earlier if women had not been experiencing any problems either during the current or previous pregnancies. Pregnant women who were young or primiparous were thought to attend late due to shame and fear of disclosing the pregnancy.

Some (n=12) participants also felt that women did not understand or value the importance of returning for follow up once a complication requiring ongoing treatment had been detected, even if they had been told by the clinician about the potential harms of not treating complications. If there was no immediate or visible consequence of a complication on the pregnancy, such as preterm labour or bleeding it was felt that women were not concerned about complying with follow up treatment:

*'I think a lot of them (the pregnant women) just can't be that bothered with coming back (for follow up treatment)...we tell them about consequences of not treating on their pregnancy or on the outcome for the baby but it doesn't seem to make a difference.'* (ZK 2)

Another participant noted:

*'They (the pregnant women) don't think many of the problems they get, like urinary infections, are such a big deal if they don't need be taken off to hospital so it doesn't matter to them if they never finish the antibiotics.'* (TA 3)

Only a small number of participants (n=4) identified communication problems between the clinicians and the women as the reason for women not attending for care when they were required. Many nursing and midwifery participants from the HCs expressed a strong sense of 'responsibility' and 'obligation' to encourage women to return for ongoing ANC and follow up. They described the extraordinary and at times intrusive efforts they made to try and achieve this, often out of their usual working hours. For example driving to several different family members' homes to locate the pregnant woman and remind her to attend for care or leaving numerous reminder messages on the woman's mobile phone:

*'I don't want it to be on my head (get the blame) if there's a bad outcome (for a baby or mother). I'll go up to their houses a hundred times and tell them to get down to the clinic for a check-up when they're overdue or need to come back for another test.'*  
(KB 9)

Despite the sense of obligation described by participants and their multiple efforts to get women to return for care, this was not considered as an effective means of improving follow up or attendance at the HC.

## **Discussion**

This mixed method study has uniquely investigated the quality of ANC using a review of both hospital and remote HC records and documented the factors influencing the delivery of this care to remote dwelling Aboriginal women.

Previous literature suggests that Aboriginal women have fewer ANC visits compared with non-Indigenous women [15-16] due to a range of factors including a lack of culturally appropriate services, sensitivity of health care providers, cost and available transport [6, 8-9, 12, 20]. In this study, the cohort of over 400 women had a mean of 9 visits with the majority of women commencing care in the second trimester. Despite women regularly accessing ANC, in this study it is the quality of this care that is found wanting.

Inadequate ANC that includes failure by health staff to provide routine screening or treatment for known risk factors and complications is recognised to contribute to potentially avoidable, poor maternal and infant outcomes, including death [11, 26-28].

Documentation around routine blood tests at the first antenatal visit and uptake of ultrasounds during pregnancy were generally good. However there was variability in screening rates for other recommended investigations as discussed below and several areas where problems were identified but not managed well, or at all, despite good evidence to support their treatment. Other Australian research has identified similar issues around poor follow up of problems detected antenatally [15, 17, 19].

Approximately 44% of pregnant Australian women participate in antenatal screening for foetal anomalies [30]. Higher rates of congenital anomalies and neural tube defects have been reported among Indigenous women compared with other Australian women

[31]. Only 75% of women who presented for ANC in the 1<sup>st</sup> trimester had a record of prescribed folate and even fewer women (9%) were offered foetal anomaly screening. This is consistent with previous research [15]. An Australian study investigating the views of remote health providers and Aboriginal women about foetal anomaly screening had similar findings identifying multiple challenges to the provision of informed consent in the area [32]. This project resulted in the development of culturally appropriate resources for Aboriginal communities and it is anticipated that the use of these resources will improve understanding and informed decision-making regarding foetal anomaly screening.

Alcohol use during pregnancy (1%) was markedly lower than that reported in other studies in regional areas (23–31%) [33-34]. This might be explained by the restrictions on the purchasing of alcohol in these remote communities and also the high proportion of women who had missing data (41%), which can underestimate these results. Similarly, smoking prevalence at the first visit (31%) was lower than in other literature (43–51%) [3, 15] and again might be explained by the high proportion of missing data in this study (45%).

There is evidence for the effectiveness of alcohol [35-36] and smoking cessation interventions during pregnancy [37-38]. The association between smoking and low birth weight (LBW) is well known [39] yet only 8% of all smokers had a record of this advice being provided at the first visit despite these communities having a LBW prevalence of 18% [40]. Research in Queensland [11] and Western Australia [41] identified that most perinatal deaths among Indigenous babies were attributed to antenatal factors that could be addressed through targeted primary health care interventions such as smoking cessation programs, to reduce the prevalence of low birth weight and preterm birth. A synthesis of Australian and international research has also identified the following 17 potentially modifiable health-related and social factors to prevent adverse birth and infant outcomes:

*alcohol use, antenatal care, birth spacing, breastfeeding, diabetes, family violence, home visits, hypertension in pregnancy, infection, nutrition, obesity, poverty, social and emotional wellbeing, Sudden Infant Death Syndrome/Sudden Unexpected Deaths in Infancy, smoking, social support and substance use [42].*

The WBM (Congress Alukura and Nganmpa Health Council Inc) [23] contains guidelines for brief interventions for smoking with a psychosocial approach recommended for pregnant women. However, there is no regular training of staff or community-based workers in these techniques. Barriers to the delivery of such interventions were emphasised by non-Aboriginal clinicians and one of the AHWs in our findings. Participants identified the need for greater involvement of Aboriginal staff in the provision of health promotion and ANC. Further education and resources to provide more successful health promotion and ANC also needs to be addressed although the effectiveness of existing resources is not well known.

Some clinicians believed that Aboriginal women did not view pregnancy as an incentive for changing harmful behaviours. They felt women had many other competing concerns such as stress associated with housing, relationship and family problems. Similar attitudes by clinicians have been identified in previous research [43]. These personal judgements influenced the clinicians' decision making and at times their adherence to guidelines. This was reflected in the poor rates of smoking cessation advice given to women.

Midwives appeared to experience a tension between not wanting to threaten the relationship with women by addressing behaviour change such as smoking, yet felt responsible to chase the women up for appointments, driving to their homes multiple times and offering transport to the clinic. These behaviours could be described as paternalistic and deny women appropriate care, disempowering them to make informed choices about their health needs and does not lead to more effective service delivery [44].

There was wide variation in routine screening for STIs, UTIs, anaemia, gestational diabetes and GBS (57–91%). Between 20% and 25% of women diagnosed with these conditions (excluding gestational diabetes) had no record of receiving the recommended treatment. This is a significant area for improvement given the high prevalence of these conditions, the evidence that exists for their screening and treatment during pregnancy [45-49] and their association with a range of complications including preterm birth, which had a 21% prevalence in these two communities [40].

Our study highlighted numerous organisational factors that impede the quality of ANC delivery. The transfer of the women between clinicians or antenatal services at the hospital and HC fragments care, creates multiple care handovers and often lacks coordination and communication (both verbal and written) between clinicians. These discontinuities in care are not just limited to the antenatal period, they also extend throughout the birth and postpartum period [50-51]. Continuity of care is a critical factor in the safety and quality of maternity care [52]. The consequences of these discontinuities in care and service organisation manifest in the high levels of incomplete follow up of identified problems during pregnancy and also during labour. One quarter of women requiring antibiotics in labour for GBS did not receive these. We do not know exactly why this is the case but it is unlikely to be due to informed refusal and more likely to result from the known discontinuities in communication and documentation that arose from the multiple, delayed or absent handovers of patient results or antenatal management plans between the HCs or hospital.

Participants described inadequate staffing levels particularly within the HCs, as a factor impacting upon the quality of care. Despite this women were seen on average nine times during their pregnancy and it was the effectiveness of care that appeared problematic. Current staffing levels or maternity services in HCs are not determined by caseload or usage patterns. The difficulty with this staffing model is also compounded by the high turnover of staff, staffing shortages and a high level of time consuming administrative tasks including coordination with the regional hospital for tests, appointments and admissions which consequently limit the time available to provide clinical care. In these communities, midwives estimated more than one third of their time is spent on administrative duties [51].

In response to this study, the data generated across the larger *1+1* project and increased resources through the national Australian government 'Closing the Gap' initiative, a continuity of carer model incorporating midwives, Aboriginal Health workers who are also student midwives, a Strong Woman Worker and cultural advisor, has been established for remote dwelling Aboriginal women when they come to the regional centre for birth. This has been evaluated as a part of the *1+1* project [53]. Other strategies to address the effectiveness of maternity services are also underway

including a designated midwife position in HCs, the expansion of community-based health workers and the training of Aboriginal midwives.

Quality improvement approaches involving monitoring of health performance and outcome indicators with regular feedback to staff have been implemented across many HCs as a way of improving staff accountability for care provision and improving the quality of care [54]. There is still an urgent need to address the cultural knowledge gaps of non-Aboriginal health providers. Maternal health skills and knowledge specific to the needs of remote dwelling Aboriginal women should form part of the core competencies for all staff providing care to these women.

Strategies suggested by Aboriginal women themselves such as legitimisation and respect for Aboriginal knowledge and skills and recognition that they make a difference to maternal infant health outcomes, and strengthening the partnership approach to health care provision with increased incorporation of two-way learning and appropriate resourcing of community-based workers (both Indigenous and non-Indigenous) [21-22] should also be at the forefront of the design of future health services in order to improve the quality of care.

The findings of this study are subject to some limitations. This study does not encompass the views of women themselves, however a related study found that some women from one of the study communities avoided maternity care due to prior negative experiences with the health services [55]. Small numbers of clinicians were interviewed in this study and these views may not be representative of all health providers working in these settings. One author (SBZ) undertook the coding and analysis of the qualitative data under supervision of author LB.

The retrospective cohort study was undertaken to provide baseline data on selected health services as part of the *1+1* project. Given the mobility of Aboriginal populations across this region [56], it is possible that women may have presented for ANC at health services other than those reviewed in this study. This may result in underestimation in service utilisation and care provision.

## Conclusion

The quality of ANC for remote dwelling Aboriginal women urgently needs to be improved. This must include the resourcing and organisation of services. At the very least, there must be comprehensive care provided and follow up for 100% of women who present for ANC, as per local guidelines. The practices and attitudes of clinicians, who do not offer Aboriginal women the same opportunity to participate in and manage their health care as other Australians, must also be addressed. A significant change to the delivery of care that incorporates strategies suggested by Aboriginal women should be seen as a priority for health care planners.

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#### **5.4 PAPER 3: Bar-Zeev S, Barclay L, Farrington C, Kildea S.**

**From Hospital to Home: The Quality and Safety of a Postnatal Discharge System Used by Remote Dwelling Aboriginal Mothers and Infants in the Top End of Australia. *Midwifery* 2012**

**Paper status:** Published

#### **Research objectives addressed in this paper:**

- To identify the barriers to quality health service delivery for Aboriginal mothers.
- To identify the barriers to quality health service delivery for Aboriginal infants.

## **Abstract**

**Objective:** to examine the transition of care in the postnatal period from a regional hospital to a remote health service and describe the quality and safety implications for remote dwelling Aboriginal mothers and infants.

**Design:** a retrospective cohort study of maternal health service utilisation and birth outcomes, key informant interviews with health service providers and participant observation in a hospital and two remote health centres. Data were analysed using descriptive statistics and content analysis.

**Setting:** a maternity unit in a regional public hospital and two remote health centres within large Aboriginal communities in the Top End of the Northern Territory, Australia.

**Findings:** poor discharge documentation, communication and coordination between hospital and remote health centre staff occurred. In addition, the lack of clinical governance and a specific position holding responsibility for the postnatal discharge planning process in the hospital system were identified as serious risks to the safety of the mother and infant.

**Conclusions and implications for practice:** the quality and safety of discharge practices for remote dwelling mothers and their infants in the transition from hospital to their remote health service following birth need to be improved. The discharge process and service delivery model must be restructured to reduce the adverse effects of poor standards of care on mothers and infants.

**Keywords:** Aboriginal, postnatal, discharge process, safety

## **Introduction**

During the early postpartum period, most mothers and infants in Australia move from acute-based maternity services to community-based services. These include general practitioner or child and family health nursing care. The manner of this transition differs across the country but usually occurs in the first two weeks postpartum though may occur as late as two months. During this period, where women move from one service to another, it is critical that they are connected with services that support their transition into the parenting process [1].

Poor service coordination or communication among health professionals can result in fragmentation of care [1]. Discontinuities in communication and documentation resulting from multiple handovers across the chain of care providers involved in transitions of care, increases risk of medical errors and compromises patient safety [2]. This risk is greatest at the time of hospital discharge when poor, delayed or absent transfer of information may result in adverse patient outcomes [3-5]. This has been demonstrated in the Northern Territory (NT) where poor communication led to the death of an elderly Aboriginal man who was flown home from hospital and left on the airstrip in his remote community. The breakdown in communication with the remote health centre (HC) meant that no one collected him from the airstrip and he was subsequently found dead [6].

The effectiveness of various mechanisms for the transfer of care from maternity to community-based services in Australia has not been assessed. It is unclear how services might best be integrated to provide optimal care for mothers and their families during the early postpartum period [1]. There is a dearth of published evidence to guide policy makers in designing this transition across services, particularly in remote settings. Few studies have investigated the consequences of health service design for remote dwelling Australian Aboriginal mothers and their infants [7-9].

The transitions of care across services for these mothers and infants, specifically in the postpartum period have not been previously studied.

The NT spans one sixth of Australia yet has only 1% of its population [10]. In stark contrast to other regions of Australia, Aboriginal and Torres Strait Islander Australians comprise 30% of the NT population with 80% living in remote locations [11-12]. The

vast geographic area and cultural diversity of the Aboriginal population, the multitude of service providers (Northern Territory Government, Aboriginal community controlled and joint national funded services), patient information systems and a high burden of maternal and infant morbidity, add to the complexity of providing an effective discharge system [13].

The prevalence of teenage pregnancy, late presentation for antenatal care, smoking [14], anaemia [15] and gestational diabetes [16] in Aboriginal and Torres Strait Islander women in Australia is higher than that among non-Indigenous women. Rates of preterm birth, low birth weight and infant mortality are twice that of non-Indigenous infants [17]. This situation requires excellent and proactive postnatal care.

The HCs provide the primary health care service in most NT remote communities. They generally operate from Monday to Friday during business hours with on call staff after hours and do not have inpatient beds. Antenatal and postnatal care in remote communities is typically provided in HCs by local or outreach services. Current practice in the NT is that remote dwelling women are transferred from their home community to a regional centre at around 38 weeks gestation to birth in a hospital [13]. Transferred women reside in hostel accommodation until the onset of labour and then give birth at the hospital with care providers with whom they are generally unfamiliar [7]. Women are frequently without personal supports during this period as the cost of transporting family members is not subsidised by government and prohibitive for families on some of the lowest mean incomes in Australia [11-12]. Following initial postnatal care in hospital, the transfer process to the HC occurs.

This model of care that is used by the majority of remote dwelling mothers is logistically complex and fragmented, involving transfer of care among multiple organisations and sectors of the health system [18]. Fragmented maternity care results in adverse outcomes [19-20]. Remote health care staff and Aboriginal women themselves have expressed major concerns about the lack of continuity of care and choice around the model of care, poor service coordination and communication across NT maternity services [9, 21-23].

The current study is nested within the National Health and Medical Research Council (NHMRC)-funded '*1+1 = A Healthy Start to Life*' project. This five-year project is



designed to improve maternal and infant health for remote dwelling Aboriginal families in two of the largest communities in the Top End of the NT. It has a mixed method, action research design with baseline data informing interventions. The project was developed in response to long standing concerns voiced by Aboriginal women, policy makers and health providers about the quality of maternity services and culturally unsafe practices [21].

This paper reports on baseline data examining the quality and safety of the postnatal transition of care from a regional hospital to remote health services.

## **Methods**

The research was conducted in two HCs located within purposively selected remote Aboriginal communities and in a 363-bed regional, public hospital in the Top End of Australia's NT. Ethical approval was obtained from the Human Research Ethics Committee of the Menzies School of Health Research and the NT Department of Health and Families.

A Continuum of Maternal and Infant Care (COMIC) assessment framework developed by the first author informed the data collection. This framework, based upon a situational analysis methodology [24], was used to assess the quality and utilisation of maternal and infant health services throughout the antenatal, birth and postpartum period and during the infant's first year of life. Qualitative and quantitative data were collected and analysed to inform health service improvements and report the views of the range of staff involved in maternal and infant care. Data collection occurred from January to August 2008. Only selected data relevant to the discharge process will be reported here with other data reported elsewhere.

### **Retrospective cohort study**

Limited data exist about the pregnancy, birth and postpartum outcomes of remote dwelling Australian Aboriginal women from the NT and their utilisation of maternal health services. We conducted a retrospective cohort study of all Aboriginal mothers from these communities who gave birth from 2004 to 2006. All Aboriginal women who gave birth to an infant at the regional hospital, in hostel accommodation, in transit to regional hospital or in the remote community from 1<sup>st</sup> January 2004 to 31<sup>st</sup> December

2006 with gestation of at least 20 weeks or birth weight of at least 400 grams, were included. The study cohort was constructed through manual data linkage between community birth records from two government-operated primary HCs and medical records at the regional hospital.

Data shown in Table 11 were collected using manual review of medical records at the hospital and HCs.

**Table 11: Maternal data collection**

| <b>Category</b>     |  |
|---------------------|--|
| <b>Demographics</b> | Age<br>Aboriginal status<br>Community<br>Employment status<br>Partner status   |
| <b>Antenatal</b>    | Gravida, Parity, Estimated data of birth<br>Past obstetric history<br>Utilisation of antenatal care (number and location of antenatal visits, routine tests and ultrasounds undertaken, outcomes and follow up of certain routine pregnancy tests)<br>Medical and pregnancy complications<br>Antenatal hospital admissions |
| <b>Birth</b>        | Place of birth<br>Labour and birth outcomes<br>Birth complications   |
| <b>Postpartum</b>   | Length of hospital stay<br>Postpartum complications up to 6 months following birth<br>Postpartum hospital admissions<br>1 <sup>st</sup> presentation to health service within 6 months following birth<br>Postnatal check in remote health service<br>Presence or absence of discharge summary at remote HC                |

Four hundred and twenty women were identified as eligible for the study. In total, 412 medical records were available for review at the hospital and 399 at the HCs.

### **Interview data**

Sixty semi-structured interviews were conducted by the first author with key health, management and administrative staff employed in the HCs (n=30), the regional hospital maternity, neonatal and paediatric units (n=18) and other staff providing clinical, administrative or logistical support for remote dwelling women during pregnancy, around the time of birth and during the first year of their infant's life (n=12) (see [Table 12](#)).

Participant selection for interviews was conducted as follows. Three of the authors identified a list of 30 potential key informants and invited them to participate in the interviews. Of these, six declined and two did not respond to the invitation. Twenty-two participants were initially recruited and interviewed. Snowball sampling was used to recruit a further 38 participants because we required expert staff who worked in very specific roles and locations for the interviews and these staff were often unknown to the authors and otherwise difficult to identify. Recruitment continued until data saturation had been reached in the analysis. Interviews included questions about the participants' role in the discharge process, their views about the current discharge process, and the strengths and weaknesses of the discharge process in relation to remote dwelling Aboriginal mothers and infants.

**Table 12: Interview participants**

| <b>Place of work</b>            | <b>Health Staff</b>  | <b>Administration</b>   | <b>Management</b>  |
|---------------------------------|--|---|--|
| <b>HC 1 (n=15)</b>              | Midwives (n=3)<br>District Medical Officers (n=2)<br>Remote Area Nurses (n=2)<br>Child Health Nurses (n=2)<br>Aboriginal Health Workers (n=2)  | HC<br>Administration<br>Staff (n=2)                                       | HC Managers<br>(n=2)   |
| <b>HC 2 (n=15)</b>              | Midwives (n=2)<br>District Medical Officers (n=2)<br>Remote Area Nurses (n=2)<br>Child Health Nurses (n=3)<br>Aboriginal Health Workers (n=3)  | HC<br>Administration<br>Staff (n=1)                                       | HC Managers<br>(n=2)   |
| <b>Regional Hospital (n=18)</b> | Midwives (n=4)<br>Doctors (n=7) ( <i>Paediatricians n=5, Obstetrician n=1, Obstetric Resident n=1</i> )<br>Special Care Nursery or Paediatric Nurses (n=2)<br>Aboriginal Health Worker (n=1) | Ward Clerk<br>(n=1)   | Hospital<br>Management<br>(n=3)  |
| <b>Other Services (n=12)</b>    | Outreach Midwives (n=4)<br>Outreach Child Health Nurses (n=2)<br>Urban Domiciliary Midwife (n=1)   | Patient Travel<br>Officer (n=1)<br>Aboriginal<br>Liaison Officer<br>(n=1) | Health<br>Services<br>Management<br>(n=1)<br>Hostel<br>Managers<br>(n=2) |

**Observational data**

Eighty hours of participant observation was undertaken by the first author, a qualified midwife, within the antenatal and postnatal units of the regional hospital and in the women's health rooms in the remote HCs. A structured observation checklist was used to obtain the data shown in Table 13. Field notes were recorded during and following interviews and observations to assist in describing the setting, behaviours, body language and non-verbal communication of the care provider.

**Table 13: Observational data collection**

| <b>Period</b>     | <b>Observation</b>   | <b>Location</b>                  | <b>Individual observations (n)</b> |
|-------------------|--|----------------------------------|------------------------------------|
| <b>Antenatal</b>  | <ul style="list-style-type: none"> <li>• Number and role of staff present during visit</li> <li>• Location of visit</li> <li>• Woman's gestation</li> <li>• Content of antenatal visit</li> <li>• Tests undertaken</li> <li>• Documentation used by staff</li> <li>• Number and type of care handovers</li> <li>• Length of time between care transfer or handover</li> <li>• Duration of visit and waiting time to be seen</li> </ul> | Regional hospital and remote HCs | n=19                               |
| <b>Postpartum</b> | <ul style="list-style-type: none"> <li>• Number and role of staff present each shift</li> <li>• Birth mode</li> <li>• Number and type of care handovers</li> <li>• Number and role of staff involved in discharge process</li> <li>• Documentation used by staff</li> <li>• Length of time between care transfer or handover</li> </ul>  | Regional hospital                | n=22                               |
|                   | <ul style="list-style-type: none"> <li>• Number and role of staff during postnatal visit</li> <li>• Content of postnatal visit</li> <li>• Documentation used by care providers</li> <li>• Number and type of care handovers</li> <li>• Length of time between care transfer or handover</li> <li>• Duration of visit and waiting time to be seen by staff</li> </ul>   | Remote HCs                       | n=6                                |

## **Data analysis**

Medical record data were entered into an Access™ (Microsoft Corporation) database and analysed descriptively using STATA™ 10.1 (Statcorp, College Station, TX, USA). Interviews were tape recorded with the participant's consent and transcribed *verbatim* along with observations and field notes. Pseudonyms were used to protect anonymity. The transcribed material, which included both qualitative and quantitative data, was analysed by the first author, using content analysis in ATLAS™ T.I 5.4 (Scientific Software Development GmbH, Berlin, Germany). The first author examined the transcriptions to identify issues and themes in the data, assigning codes to units of meaning apparent in each paragraph or sentence. The first and second author then discussed the codes until consensus was reached. Data were then consolidated into higher-level categories and core themes identified. Content analysis was then undertaken to ascertain frequencies evident within the core themes. We used multiple sources of data (interview, observational and retrospective cohort study data) to validate our findings around the issue of the quality of care received by women and babies in relation to the discharge process.

## **Findings**

Ninety per cent of the births took place at the regional hospital whereas the remaining births were in the remote community, in transit to hospital or at hostel accommodation within the regional centre (10%).

### **Regional hospital cohort**

The mean age of the mothers who birthed at the regional hospital (n=371) was 23 years (range 13–41) and 55% were multiparous. Most mothers (65%) had an unassisted vaginal birth, 28% had a caesarean section and the remaining women had an instrumental (6%) or breech vaginal birth (1%). Postpartum haemorrhage occurred in 25% of hospital births with 8% of women experiencing a postpartum hemorrhage greater than 1000mL. Nineteen per cent of all hospital births were preterm.

## **Postnatal model of care and discharge systems**

Following birth in the delivery suite or operating theatre, early postnatal care of the mother and infant was observed to be provided by staff attending the birth. Mother and infant were then transferred to a shared or occasionally single room in a busy antenatal/postnatal unit and care handed over to different staff. In general, the staff were unknown to the mother. The mean length of hospital stay was three days (range 4 hours to 23 days). During this period mothers and their infants were observed to receive direct patient care from two to 15 different individual health care providers (registered midwives, nurses, student midwives and doctors) with multiple care handovers, usually occurring at every shift change. Over a three day admission, the average number of different care providers observed per mother was nine. Some mothers and infants also received additional care from lactation consultants and physiotherapists.

Discharge information which comprised a discharge summary, birth summary and neonatal checklist were compiled and completed by two or three staff members, and their timely completion delayed if test results or other information was pending. On other occasions, a fourth staff member was responsible for sending the discharge summary to the HC. This task was not always completed at the time of discharge. As part of the hospital discharge planning process, mothers were advised to return to their HC for a six-week postnatal check or earlier if needed and to take their infant for a visit upon their return home. Following discharge, remote dwelling mothers either returned directly to their home community or to a temporary residence such as a friend or relative's home or hostel in the regional centre while awaiting their flight home. One of the study communities was serviced by an airline that instituted a policy restricting travel to infants under one week old, thus delaying their return home.

Some mothers received domiciliary postnatal care in their temporary residence up to day 10 following discharge, although the provision of these visits was inconsistent. Reasons described by health providers for inconsistency in service delivery in this context included patient mobility following hospital discharge, miscommunication between the health providers and the mothers about the timing and location of the

postnatal visit and the perception by health providers that mothers do not value the postnatal visit sufficiently to make it worthwhile for them to undertake.

The majority of HC staff (n=21/30), around half (n=10/18) of regional hospital staff and most (n=9/12) of the other staff identified significant problems with the postnatal discharge processes. The following case study illustrates these intersecting issues that have been identified in the study. Most commonly occurring problems identified in the analysis were poor written information transfer, poor verbal communication, lack of coordination between the hospital and the remote health services, lack of clinical governance and leadership and poor knowledge of roles and work practices in HCs by hospital staff.

### **Case study**

Tina, aged nineteen, gave birth to her first baby at the regional hospital. She had a caesarean section for 'failure to progress' and a subsequent wound infection and mastitis during her inpatient stay. Tina was commenced on antibiotics on day five and discharged on day nine. She stayed with relatives near the hospital until her flight back to her home community on day twelve.

Tina presented to her HC centre upon her return, febrile and feeling very unwell. She had asked to see the midwife as she had been told by a doctor in hospital that 'the midwife would give her treatment at the health centre' when she returned to her community. The HC midwife was unaware that Tina had been discharged from hospital and did not have any information about Tina's inpatient stay at a hospital.

The discharge summary had not been sent to the HC. Tina did not receive a copy of the summary when she was discharged. The midwife spoke with Tina in an attempt to gain information about her birth and inpatient stay. English was Tina's second language and she did not understand the reason for her caesarean section. She could only tell the midwife that the hospital doctor had said she needed 'treatment' for her painful breasts.

The midwife was required to make numerous phone calls to the hospital to ascertain information about the woman and spoke with five different staff members (ward clerk, two midwives, a resident and a registrar) in order to obtain a complete history. This process took more than two hours of the midwife's time. The midwife was then required to contact the medical records department and fax through a request form to obtain the discharge



summary. She waited a further 50 minutes for the summary to be located and faxed back to the HC.

The discharge summary was located by medical records staff in the patient history. It specified that Tina required daily caesarean wound care, support with breastfeeding attachment, which had been difficult for Tina from birth, continued antibiotics, blood tests and a medical review upon return to her community. The discharge summary had never been sent from the hospital. Tina was reviewed again by the midwife at home later that evening; she was becoming increasingly unwell and was subsequently evacuated back to the hospital with sepsis and required a further seven day inpatient stay.

### **Information transfer and poor communication**

Lengthy delays or outright absence of discharge summaries sent from the hospital to the HC were described by HC participants as the most serious problem:

*'I saw a primip...a shy young girl...(she) came up to the health centre a few weeks after having her baby...I didn't have a (discharge) summary from the hospital...she was given medicine from the hospital to take at home...but she didn't know what for and I couldn't tell her either because I didn't have any information...It can be absolutely frustrating for us out here...It's like we get just left out of the picture by the hospital...like we don't count.'* (HC Midwife)

The regional hospital policy is for discharge summaries to be completed within 48 hours of discharge. Ideally this occurs prior to discharge and the mother is given her own copy to take home, one copy is to be sent to her GP or HC if she lives in a remote community and a third copy to be filed in the hospital medical record.

The practice of mothers being given their own summary upon discharge was inconsistently performed. The most common reason given by staff for mothers not being provided their own copy was that paperwork was not always complete at the time of discharge, with staff citing competing priorities of managing busy and complex patient workloads.

Other reasons reported included staff being unable to locate the mother at the time of discharge and lack of trust by hospital staff that mothers could reliably take their own summary back to their HC. One hospital participant reported that if mothers were given

the summary they *'wouldn't read it anyway...who bothers with those forms?', '(they) would just lose them' [or] 'throw them in the bin on the way out...I see that happen all the time' .*

Health centre participants reported receiving hospital summaries *'sometimes months after the mother has been discharged or not at all'*. Eleven per cent of maternal records reviewed at the HCs did not have a discharge summary for the birth that occurred during 2004–2006.

Most HC participants described the hospital as the primary source of the discharge information transfer problem with a few acknowledging the role of their own HC for the discontinuities in the flow of information between administration staff and clinical staff:

*'Well we can't always go blaming the hospital system...I know they (the hospital) often send out the discharge summaries...but sometimes those summaries just sit in a big pile of filing in reception and never get handed to us (midwives) by reception staff...there are lots of gaps in the system where important information seems to just vanish.'* (HC Midwife)

The consequences of absent or delayed discharge summaries on mother and infant care described by HC participants were numerous. The most frequently reported consequences were missed opportunities by HC staff to follow up the mother and infant upon their return to the community and provide postnatal and newborn checks (n=26/30), parenting support (n=26/30), ongoing management of postnatal complications (n=21/30) and the failure to have medication regimes implemented or tests administered (n=20/30) or pending test results followed up (n=12/30). Other mothers and infants were reported to have had missed outpatient appointments back at the regional centre due to the lack of information and communication.

The administrative burden and excess time wasted by staff following up absent summaries was reported as substantial. Incorrect, conflicting or missing discharge information such as medication doses, birth complications and reasons for caesarean section were observed multiple times in medical records and confirmed by participants:

*'You ring the (postnatal) ward and try to speak to a doc or midwife who was involved with the woman's care in hospital to piece together the missing information...and invariably, the doc is busy and doesn't call you back...or is on days off.'* (HC Midwife)

*'I saw a woman whose discharge summary said she had a vaginal birth with a 3<sup>rd</sup> degree tear...then I asked her what happened in her birth and she said 'I had an operation in the middle....a caesarean' so I don't know where this other information has come from. You begin to wonder if all the other stuff you read is true or if they got the right lady to start with!!'* (HC Midwife)

### **Lack of clinical governance and leadership**

Hospital participants described a lack of clinical leadership in addition to the high staff turnover and multiple staff engaged in the discharge process, as reasons why discharge processes were often problematic:

*'We have known about the problems between here (at the hospital) and remote (HCs) for years...they are always hard to resolve unless you get someone to step up and specifically take on the responsibility to see that the problem gets fixed....(this is) always hard in such a frantic workplace.'* (Hospital Midwife)

Participants from both the HC and the hospital spoke of the importance of improving the 'links', 'connections' and 'associations' between the two health systems as a means of improving the continuity of care and the communication process. Designated leadership positions including a discharge coordinator were seen as the most effective way of achieving this:

*'We need more positive links between the hospital and health centres...a midwife (at the hospital) who knows all the women from the communities...who can update health centres about how the women are going in hospital, what's been happening with the baby and ring them when they are planning on discharge.'* (Hospital Management – Midwifery)

## **Lack of knowledge and understanding of roles and work practices in health centres**

Health centre participants expressed frustration at the lack of understanding by hospital staff of their roles within a remote primary health care service and felt that staff did not understand that the HC was not *'an outback version of a busy city hospital'* (*Remote HC Management*). Participants described cases whereby women had been discharged home from hospital with inadequate supplies of medication, infant artificial milk or dressings that were not readily available in HCs or remote communities that do not have pharmacies:

*'I saw this ex-preemie out here...her grandmum and mum brought her up to the clinic for a weigh and I got the summary out and it said 'mother to breastfeed 2-3 hourly, express with pump and top up with a bottle'. I found out she (the mum) had never used a pump let alone own one...I rang the nurses (at the hospital) and this young one said to me 'Oh I thought you would have them (the pumps) to hire to the mums out there'... we don't...so I had to then spend the next few hours trying to teach this young mum how to hand express and work out how she was going to store milk...we had to get bottles and teats and formula and teach her how to use them and clean them. They just expect it would just magically happen for her out here.'* (*HC Child Health Nurse*)

Staff interviewed from HCs also felt that hospital staff had unrealistic expectations of the type of care that could be provided in a remote HC such as requesting a midwife to visit a mother at home multiple times per day for breastfeeding support. Health centres across the NT differ in their provision of maternal and child health services. One community had a midwifery service available two days per week whereas the other had a full time service. Lack of time due to high workloads focused on the delivery of acute care and staff shortages within the HC, as well as a lack of transport for staff were cited as reasons that often prevent home visits or indeed any postnatal care from being undertaken.

## **Joint discharge planning**

Participants interviewed from HCs often claimed that hospital staff did not fully understand the way HCs functioned *'unless they've spent time out here on the ground themselves'* (*Remote District Medical Officer*). They also stated that hospital staff did not

know the consequences of the poor discharge practices on patient outcomes and the implications for remote staff trying to deliver effective postnatal care.

This lack of understanding and appreciation of the way the 'other' service functions was identified as a major contributing factor in the breakdown of coordination between the remote and regional health services:

*'The hospital doesn't understand what's achievable out here – it's doing it their way and not recognising the expertise out here in the health centre...how things work.'* (HC Nurse)

One third of HC and hospital participants suggested joint discharge planning case conferences, which could be conducted by phone, as a way of providing more effective discharge care and improving collaborative relationships. These case conferences would involve multidisciplinary hospital and HC staff and focus on individualised discharge planning, particularly for women requiring complex postnatal care in the community:

*'We (the remote doctors) absolutely need to be more involved in the discharge planning for these women and families when they get sent into hospital...a case conference or something needs to happen so that we can fill the hospital doctors in about the best way to manage the family...and work together to make the right decisions...especially about ongoing treatment that will end up happening out here in the community with us.'* (HC District Medical Officer)

Further recommendations made by both HC and hospital staff to improve the discharge planning process included the introduction of a comprehensive, multidisciplinary discharge planning pathway or a 'care map' that would commence in pregnancy and could be used by the HC and hospital staff, and a routine phone call made by postnatal staff to the HC midwife to inform them of the woman's birth outcomes and to discuss discharge plans.

### **What works well?**

Only one fifth of all participants identified one or more strengths with the current discharge process. Comprehensive orientation to discharge process at the

commencement of employment and the presence of some senior staff who had knowledge of both the hospital and HC health system were identified as the main strengths of the discharge process.

## **Discussion**

In many Western countries, hospital-based postnatal care is often a neglected area of maternity service delivery and 'rarely viewed or planned as part of a continuum of planned, effective maternity care for individual women' [25, p8]. This experience has been highlighted in this study with remote dwelling Aboriginal women.

The transfer of mother and infant care from the hospital to the remote health service is fragmented with major discontinuities in care. The inconsistent, *ad hoc* and chaotic nature of communication, at times entirely absent can result in serious clinical consequences for new mothers and their infants during an already vulnerable period.

Common problems reported by HC providers were missing discharge summaries or summaries with inaccurate or incomplete information. These findings are consistent with a previously published study that also identified problems in accuracy, timeliness and completion of discharge paperwork and high rates (18%) of missing summaries in HCs across the NT [26]. There appears to be little improvement over the past decade.

The lack of coordination between the regional and remote health services was manifest in limited communication between staff, lack of understanding of the role and capacity of HC staff and a lack of clear responsibility for discharge planning at the regional hospital. This compromised the quality and safety of mothers and infants in the transition of care across the services. Such problems arising in the transition of care across health services are well documented [1, 21, 27, 28] and are frequently due to breakdown in communication and coordination across services. These problems were further exacerbated by the remote geography of the NT, the fact that many women speak little English and often do not understand the treatment they have had and the complex social and health situation of Australian Aboriginal women [13].

Multiple caregivers are involved in the delivery of care during the antenatal, birth and postnatal periods as women transition between health services in their remote home communities and regional hospital and then back to the community following birth.

Evidence links a lack of continuity of care with increased intervention during labour, maternal dissatisfaction with care and increased costs per birth [19-20, 29]. Aboriginal women vulnerable to poorer perinatal outcomes tend to be adolescent, have poor attendance at antenatal care and suffer socioeconomic disadvantage [30]. Women with these vulnerabilities are at particular increased risk from discontinuities in care.

Strengths of this study include the use of a broad range of data that enables pragmatic strategies for improvements in the postnatal discharge system and inclusion of a wide range of interview participants working across all areas of maternity services in both regional and remote health settings. These findings have been reported to Local Reference Groups in the study communities and an Advisory Group comprising health management, policy and clinical staff from the hospital, HCs and the NT Department of Health and Families. A number of improvements to the discharge system have subsequently been implemented including the redesign of summaries, introduction of electronic discharge and data linkage systems and hospital staff training to address discharge summary dispatch issues [31].

Limitations of this study include the use of a snowball sampling process to recruit interview participants. Although it was very useful for identifying difficult to reach staff, particularly in remote settings, it is important to acknowledge that there may have been a sampling bias as it was difficult to know if the sample was truly representative of the wider population. A further limitation is the absence of views from the mothers themselves. However, a related study does include their experience and has found that one in 10 pregnant women avoid the health service for birth, for reasons including prior negative experiences with the health service [9].

In response to this study and the evidence generated across the larger study, a continuity of care model designed for remote dwelling Aboriginal women has been piloted in the NT with concurrent evaluation being undertaken.

### **Conclusion and implications for practice**

More effective collaboration between sectors of health services and professionals themselves are the key to improving quality and safety of discharge care. Implementation of an integrated model of care for all remote dwelling women, which includes clearly defined standards of practice and responsibility and accountability for

discharge planning are needed if quality and safety improvements are to be achieved. Regular monitoring and feedback against performance indicators, such as accuracy and timeliness of dispatch of discharge summaries, also needs to be undertaken. Above all, regular communication and rapport between the health services is critical to develop a more integrated system of service that places the needs of the mother and infant at the core.

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**5.5 PAPER 4: Bar-Zeev S, Kruske S, Barclay L, Bar-Zeev N, Carapetis J, Kildea S.**

**Use of Health Services by Remote Dwelling Aboriginal Infants in Tropical Northern Australia: A Retrospective Cohort Study. *BMC Pediatrics* 2012**

**Paper status:** Published

**Research objectives addressed in this paper:**

- To describe the patterns of health service use by Aboriginal infants at the remote health centre and the regional hospital during their first year.
- To document the state of health among Aboriginal infants during their first year.

## **Abstract**

**Background:** Australia is a wealthy developed country. However, there are significant disparities in health outcomes for Aboriginal infants compared with other Australian infants. Health outcomes tend to be worse for those living in remote areas. Little is known about the health service utilisation patterns of remote dwelling Aboriginal infants. This study describes health service utilisation patterns at the primary and referral level by remote dwelling Aboriginal infants from northern Australia.

**Results:** Data on 413 infants were analysed. Following birth, one third of infants were admitted to the regional hospital neonatal nursery, primarily for preterm birth. Once home, most (98%) health service utilisation occurred at the remote primary health centre, infants presented to the centre about once a fortnight (mean 28 presentations per year, 95% CI 26.4–30.0). Half of the presentations were for new problems, most commonly for respiratory, skin and gastrointestinal symptoms. Remaining presentations were for reviews or routine health service provision. By one year of age 59% of infants were admitted to hospital at least once, the rate of hospitalisation per infant year was 1.1 (95% CI 0.9–1.2).

**Conclusion:** The hospitalisation rate is high and admissions commence early in life, visits to the remote primary health centre are frequent. Half of all presentations are for new problems. These findings have important implications for health service planning and delivery to remote dwelling Aboriginal families.

## **Background**

Australian Aboriginal people have dramatically worse health outcomes than non-Aboriginal people by every measure, and this is as true for children as it is for adults [1]. Although most Aboriginal people reside in cities and regional areas, approximately one quarter live in remote communities [2]. Health outcomes for Aboriginal people in remote communities tend to be worse than those in larger rural or urban centres [3].

Aboriginal newborns have higher rates of perinatal mortality, preterm birth and low birth weight than non-Aboriginal newborns [4]. Aboriginal infants also have a higher burden of illness and hospitalisation than non-Aboriginal infants [5]. Despite improvements in perinatal mortality [6] incidence rates of certain infectious diseases continue to be among the highest in the world [7].

In the Northern Territory (NT), where Aboriginal Australians comprise 30% of the population [8], respiratory and diarrhoeal diseases are the leading causes of hospitalisation for Aboriginal infants and children [9]. This burden of illness commencing in infancy foreshadows the early onset of chronic disease [10]. Aboriginal infants from remote communities in the East Arnhem region of northern Australia are frequent users of primary health services presenting on average twice per month, mostly for upper respiratory tract and skin infections [11].

Access to appropriate, high quality health care during infancy and indeed throughout all stages of life, is considered a basic human right [12] and essential to reducing morbidity and mortality [13], but remote dwelling Aboriginal adults have less access to health services than other Australians [14]. Barriers to access include the availability of and distance from health services, transport, English proficiency [15] and insufficient attention to the cultural needs of Aboriginal people [16].

Data on health service access and utilisation by remote dwelling Aboriginal infants are limited. Planning of health services must be informed by an understanding of service utilisation patterns, particularly at the primary level. We therefore aimed to document comprehensively the health service utilisation of a cohort of Aboriginal infants born in remote NT communities.

## **Methods**

### **Setting**

The study sites were the health centres (HCs) in two large purposively selected remote Aboriginal communities in northern Australia, located approximately 500km from the major urban centre, Darwin. The regional hospital in Darwin is the single public hospital servicing these communities and provides comprehensive tertiary, paediatric and newborn care.

Health care in remote HCs is typically provided by remote area nurses (RANs), and Aboriginal Health Workers (AHWs), with doctors consulting patients referred to them by these staff. Onsite staff are often supported by visiting paediatricians and child health nurses. Infants requiring hospitalisation are evacuated from the community to the regional hospital, approximately one-hour flight by light airplane.

### **Design and data collection**

We conducted a retrospective cohort study of Aboriginal infants from these communities, following them up to 12 months of age. All Aboriginal infants born 1<sup>st</sup> January 2004 to 31<sup>st</sup> December 2006 with gestation of at least 20 weeks or birth weight of at least 400g and born at the regional hospital, in hostel accommodation, in transit to hospital or in the remote community, were eligible for inclusion in the study. The study cohort was constructed through manual data linkage between community birth records from two government operated primary HCs and medical records at the regional hospital.

Data were collected using manual review of medical records at the hospital and HCs. We collected the number of episodes and reason for health service utilisation at the HC, categorising reasons for presentation according to the local guidelines for treatment of children (see Table 14) [17]. Primary and additional reasons for each presentation were recorded; multiple presentations occurring on the same day were separately enumerated. The number of hospital admissions and reason for admission were also recorded. Hospital admissions were categorised by discharge diagnoses from the discharge summary or the medical record if the summary was not available. We also recorded admissions to the regional hospital Neonatal Nursery Unit (NNU). We only

included NNU admissions that lasted 4 hours or more, reasoning that some infants transited briefly through the NNU when it was uncertain if they actually required admission. Hospital outpatient visits were not included as part of this study. Many infants receive this follow up in the remote HCs by visiting specialists and this was included as part of the HC utilisation data collection.

**Table 14: Categorisation and recorded reason for presentation at the health centre**

| <b>Category</b>                              | <b>Documented reason for presentation</b>   |                        |                        |              |               |              |                            |       |                                      |                           |        |  |               |        |                |                           |                        |  |  |
|--|---|------------------------|------------------------|--------------|---------------|--------------|----------------------------|-------|--------------------------------------|---------------------------|--------|--|---------------|--------|----------------|---------------------------|------------------------|--|--|
| New problem                                  | <table border="0"> <tr> <td>Breastfeeding problems</td> <td>Other feeding problems</td> </tr> <tr> <td>Ear symptoms</td> <td>Other reasons</td> </tr> <tr> <td>Eye symptoms</td> <td>Respiratory tract symptoms</td> </tr> <tr> <td>Fever</td> <td>Seizures/other neurological symptoms</td> </tr> <tr> <td>Gastrointestinal symptoms</td> <td>Sepsis</td> </tr> <tr> <td>Infant supplies: formula/food/medicine</td> <td>Skin symptoms</td> </tr> <tr> <td>Injury</td> <td>Social reasons</td> </tr> <tr> <td>Non-acute newborn reasons</td> <td>Urinary tract symptoms</td> </tr> <tr> <td>No symptoms/reason for presentation recorded</td> <td></td> </tr> </table> | Breastfeeding problems | Other feeding problems | Ear symptoms | Other reasons | Eye symptoms | Respiratory tract symptoms | Fever | Seizures/other neurological symptoms | Gastrointestinal symptoms | Sepsis | Infant supplies: formula/food/medicine | Skin symptoms | Injury | Social reasons | Non-acute newborn reasons | Urinary tract symptoms | No symptoms/reason for presentation recorded |  |
| Breastfeeding problems                       | Other feeding problems  |                        |                        |              |               |              |                            |       |                                      |                           |        |  |               |        |                |                           |                        |  |  |
| Ear symptoms                                 | Other reasons   |                        |                        |              |               |              |                            |       |                                      |                           |        |  |               |        |                |                           |                        |  |  |
| Eye symptoms                                 | Respiratory tract symptoms  |                        |                        |              |               |              |                            |       |                                      |                           |        |  |               |        |                |                           |                        |  |  |
| Fever  | Seizures/other neurological symptoms  |                        |                        |              |               |              |                            |       |                                      |                           |        |  |               |        |                |                           |                        |  |  |
| Gastrointestinal symptoms                    | Sepsis  |                        |                        |              |               |              |                            |       |                                      |                           |        |  |               |        |                |                           |                        |  |  |
| Infant supplies: formula/food/medicine       | Skin symptoms   |                        |                        |              |               |              |                            |       |                                      |                           |        |  |               |        |                |                           |                        |  |  |
| Injury                                       | Social reasons  |                        |                        |              |               |              |                            |       |                                      |                           |        |  |               |        |                |                           |                        |  |  |
| Non-acute newborn reasons                    | Urinary tract symptoms  |                        |                        |              |               |              |                            |       |                                      |                           |        |  |               |        |                |                           |                        |  |  |
| No symptoms/reason for presentation recorded |   |                        |                        |              |               |              |                            |       |                                      |                           |        |  |               |        |                |                           |                        |  |  |
| Routine health check                         | <ul style="list-style-type: none"> <li>Well baby check</li> <li>Immunisation</li> <li>Growth Action and Assessment (GAA) *</li> <li>Anaemia monitoring</li> </ul>   |                        |                        |              |               |              |                            |       |                                      |                           |        |  |               |        |                |                           |                        |  |  |
| Review visit                                 | Planned follow-up visit specifically requested by any HC staff or visiting medical, nursing or allied health specialists (excluding paediatricians). These visits are typically used to review infants following an acute presentation or for ongoing monitoring and management of chronic problems   |                        |                        |              |               |              |                            |       |                                      |                           |        |  |               |        |                |                           |                        |  |  |
| Paediatric review                            | Onsite consultation with outreach visiting paediatrician  |                        |                        |              |               |              |                            |       |                                      |                           |        |  |               |        |                |                           |                        |  |  |

\*GAA was a NT Government program for remote dwelling children under five years at the time of the study. It was designed to improve growth and nutritional status through monitoring of growth and anaemia and intervention of growth faltering.



Primary endpoints were the number of primary health care episodes and hospital admissions. Person-time observed commenced at birth and ceased on the day the infant turned one year old or the date the infant died.

## **Ethics**

Ethical approval was obtained from the Human Research Ethics Committee of the Menzies School of Health Research and the NT Department of Health and Families. The data presented here is from a baseline study nested within the National Health and Medical Research Council '1+1 = A Healthy Start to Life' project. This five year project aimed to improve maternal and infant health for remote dwelling Aboriginal families in the NT.

## **Statistical analysis**

Data were analysed per infant and per presentation using STATA™ 11.1 (Statcorp, College Station, Texas). Continuous data are reported as means (1 standard deviation (SD), 95% Confidence Interval (CI)) or medians (Interquartile Range (IQR)) and compared using 2-tailed t-test assuming unequal variances if appropriate. Dichotomous data are reported as proportions and compared using  $\chi^2$ -test. Wilson confidence intervals are reported for binomial proportions.

## **Results**

Four hundred and fifty-two births were identified. Excluded were non-Aboriginal infants (n=26) and infants born in a hospital other than the regional hospital (n=2). Of the 424 eligible infants, 11 (2.6%) had no community or hospital record. The final cohort consisted of 413 infants, 399 of whom had both hospital and community records, 9 had a hospital record only and 5 a community record only (all born in the community and never admitted to hospital). In total, 408 infant records were reviewed at the hospital and 398 at the HCs. Birth outcome data was obtained from maternal records where infant records were unavailable.

## **Birth**

Ninety per cent (n=371) of the 413 infants were born at the regional hospital (inborn). Ten per cent were outborn; 38 of these infants were born in the remote community, and

4 were born in transit to hospital or at hostel accommodation in the regional centre. Outborn infants had significantly lower gestational age and birth weight than inborns. Mean gestation for inborns was 37.6 weeks (SD 2.6, 95% CI 37.3–37.9), for outborns 36.2 weeks (SD 3.6, 95% CI 35.0–37.2);  $p=0.001$ . Mean birth weight for inborns 2998g (SD 629, 95% CI 2933–3062), for outborns 2726g (SD 837, 95% CI 2477–2974);  $p=0.008$ . The proportion of low birth weight (LBW) infants (<2500 grams) was 16% among inborns and 35% among outborns;  $p=0.002$ . The proportion of preterm infants among inborns was 19% and 36% among outborns. In total, 21% of infants were born preterm (<37 weeks gestation) and 18% were low birth weight.

### Neonatal Nursery Unit admissions

Overall, one third of infants were admitted to the NNU for 4 hours or more. Most frequently recorded NNU discharge diagnoses are summarised in Table 15. Infants could have multiple discharge diagnoses recorded on discharge summaries.

**Table 15: Neonatal Unit discharge diagnoses**

| Discharge diagnoses                 | Number (%) |
|-------------------------------------|------------|
| Preterm                             | 61 (50%)   |
| • 32–36.6 weeks                     | 42 (35%)   |
| • 28–31.6 weeks                     | 11 (9%)    |
| • <28 weeks                         | 8 (6%)     |
| Low birth weight (<2500g)           | 60 (50%)   |
| • 2000–2499                         | 34 (28%)   |
| • 1500–1999                         | 7 (6%)     |
| • <1500                             | 19 (16%)   |
| Presumed sepsis                     | 29 (24%)   |
| Respiratory illness                 | 25 (21%)   |
| Respiratory Distress Syndrome       | 16 (13%)   |
| Transient tachypnoea of the newborn | 9 (8%)     |
| Intrauterine growth restriction     | 13 (11%)   |
| Diabetic mother                     | 10 (8%)    |
| Other maternal illness              | 8 (6%)     |
| Congenital anomalies                | 6 (5%)     |
| Cardiac problems                    | 6 (5%)     |

Mean gestation (weeks) for infants admitted and not admitted to NNU respectively was 35.5 (SD 3.8, 95% CI 34.8–36.1) and 38.3 (SD 1.7, 95% CI 38.1–38.5);  $p < 0.001$ . Mean birth weight for infants admitted and not admitted to NNU respectively was 2524g (SD 828, 95% CI 2374–2673) and 3150g (SD 468, 95% CI 3096–3204);  $p < 0.001$ .

### **Health centre presentations**

A total of 11,224 episodes of remote health service utilisation were made by the 398 infants with a community record. The median time from hospital discharge to first utilisation of the health service was 8 days (IQR 4–19) with 96% of presentations occurring at the HC and 4% at home. Two neonatal deaths occurred following hospital discharge.

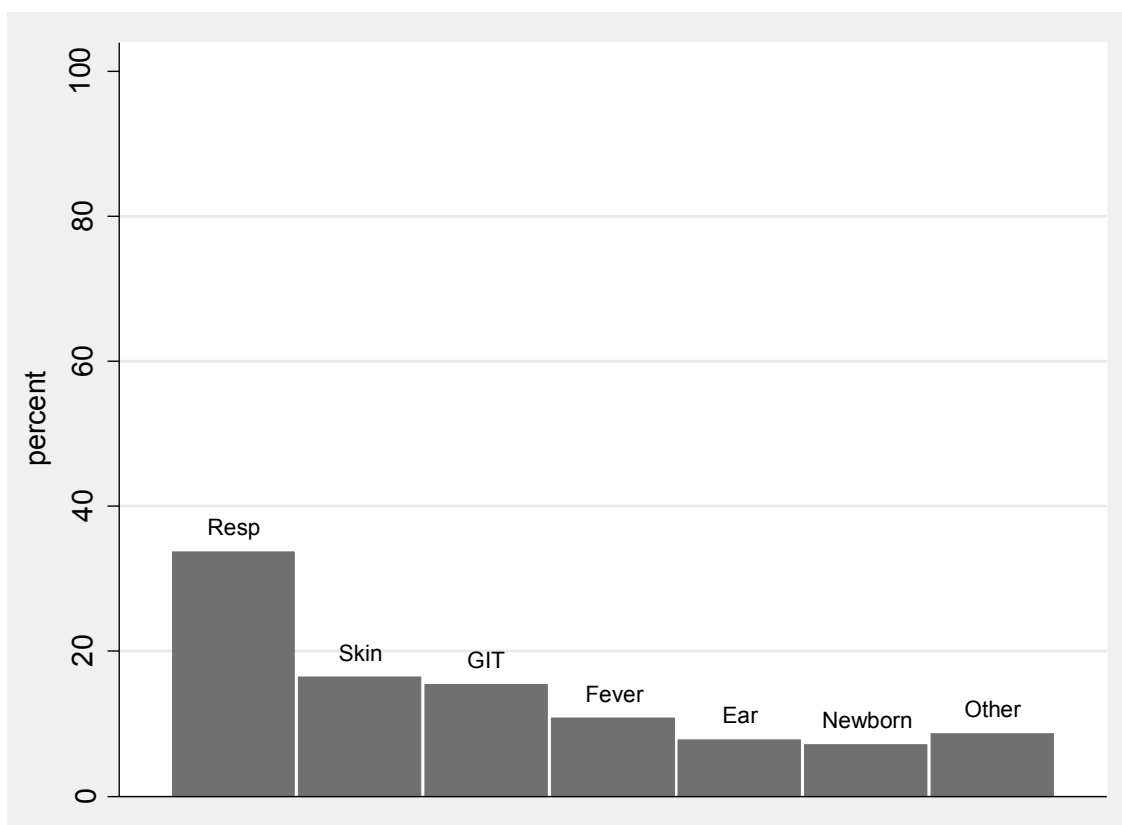
First presentations were for routine health checks (80%), acute symptoms (13%) and non-acute newborn reasons (7%).

### **Frequency of presentations**

Infants presented to the HC between 1 and 186 times during the first year of life, median 25 (IQR 15–38), mean 28 (SD 18, 95% CI 26.4–30.0). Infants previously admitted to NNU had on average 33 presentations (95% CI 29–37), compared to 26 presentations (95% CI 24–28) for infants not previously admitted to NNU;  $p < 0.001$ .

### **Reason for presentation**

New problems were the most common reason for HC presentations (49%). These were predominantly for respiratory (resp), skin and gastrointestinal (GIT) symptoms (Figure 7). Routine health checks comprised 34% and review visits: 15% by HC staff or other visiting specialists and 2% by outreach paediatricians. Fourteen infants (3.5%) collectively had 1137 (10.1%) visits, an average of 81 visits per infant. The reasons for presentation among this group did not differ to the rest of the population.



**Figure 7: Primary reason for new presentation to the health centre (excluding review and routine visits)**

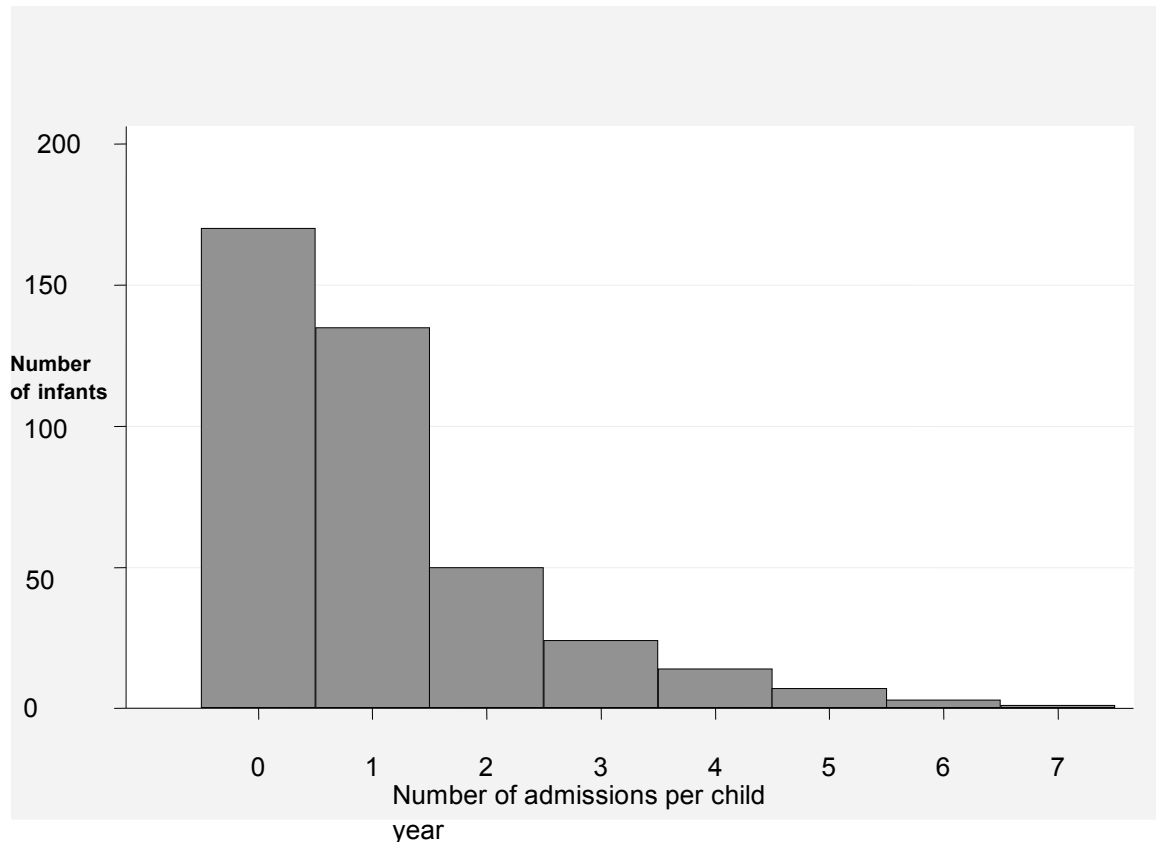
### **Age at presentation**

Age at presentation was uniformly distributed throughout the first year, implying that the high rate of utilisation remained consistently high throughout the entire first year of life. In the 0–3 month age group, respiratory, skin symptoms and non-acute newborn reasons made up the bulk of reasons recorded for new problems. Presentations related to newborn reasons declined after 3 months with respiratory, skin and gastrointestinal symptoms, non-specific fever and ear symptoms dominating subsequent visits.

### **Hospital admissions in first year**

By one year of age 59% of infants were admitted to hospital at least once; the rate of hospitalisation including NNU admissions was 1.1 (95% CI 0.9–1.2) admissions per infant. The rate of admission for infants previously in NNU was more than double that among non-NNU admitted infants ( $p < 0.001$ ).

Among admitted infants, 58% had one admission, 21% two and 21% had between three and six admissions (Figure 8).



**Figure 8: Number of infant hospitalisations in the 1<sup>st</sup> year including Neonatal Nursery Unit admissions**

Excluding NNU admission, 47% of infants required hospital admission in the first year of life and the hospitalisation rate per infant was 0.78 (95% CI 0.70–0.88). Of the infants who were admitted to the NNU, 60% were readmitted within the first year. Overall, of the infants born preterm, 60% were readmitted compared with 44% of term babies.

The median age at first hospitalisation excluding NNU admitted infants was 4.6 months (IQR 2.7–7.3 months). Hospital admissions were predominantly for respiratory infections and gastroenteritis (Table 16).

**Table 16: Hospital diagnosis**

| <b>Diagnosis</b>                         | <b>Primary diagnosis<br/>Total (%)</b> | <b>Secondary diagnosis<br/>Total (%)</b> |
|--|--|--|
| Respiratory infections                   | 145 (47%)                              | 5 (2%)                                   |
| Gastroenteritis                          | 85 (27%)                               | 2 (1%)                                   |
| Failure to thrive                        | 14 (5%)                                | 6 (2%)                                   |
| Other                                    | 12 (4%)                                | 2 (1%)                                   |
| Skin infection                           | 10 (3%)                                | 3 (1%)                                   |
| Fever without focus/<br>suspected sepsis | 9 (3%)                                 | 1(<1%)                                   |
| Urinary tract infection                  | 7 (2%)                                 | 4 (1%)                                   |
| Surgery                                  | 7 (2%)                                 | 1 (<1%)                                  |
| Seizures                                 | 5 (2%)                                 | 1 (<1%)                                  |
| Anaemia                                  | 4 (1%)                                 | 4 (1%)                                   |
| Injury                                   | 3 (1%)                                 | 0  |
| None recorded                            | 9 (3%)                                 | 281 (91%)                                |
| <b>Total</b>                             | <b>310</b>                             | <b>310</b>                               |

## **Discussion**

This study has uniquely described patterns of health service utilisation in the total infant population of two of the biggest remote communities in Australia's Northern Territory. We have documented extremely high rates of health service utilisation at the primary and referral level, commencing from birth and continuing throughout the first year. Remote dwelling Aboriginal infants access health care frequently for both routine and acute care, despite the multiple barriers to care outlined by others [15, 16].

There were a total of 11,224 presentations to the HCs for the three years of data collection. For each community, this translates to an average of 7.65 infant presentations per day (based on 249 working days in the year). The implications of this for remote workforce planning are important given that most HC presentations were for new, acute problems. The severity and complexity of many presentations in these HCs can require multiple staff to provide numerous hours of acute care to an individual infant, particularly when the infant needs emergency air evacuation to hospital. Cultural and linguistic barriers as well as staffing shortages, a lack of nurses with child health

skills and qualifications and rapid turnover resulting in repeated training of new staff [18] compound this workload in remote health services. The organisation and delivery of infant health services in remote northern Australia varies across HCs. Some HCs have specific days for routine health checks by designated staff, with the acute care delivered by other staff as needed. Other communities have designated staff that deliver both routine and acute care any time that the infant presents to the HC.

Service provision is dependent upon HC funding (staffed for a 5-day week, minimal weekend service and on call service afterhours; not 24/7 service provision), availability of staff (relief not always provided for holidays or educational leave), callouts the previous night, staff skill mix and community size. Current staffing levels for infant and child health services in remote communities are not determined by their burden of disease or service usage and are insufficient to meet the needs of the young population, thus affecting the quality of care [18].

We distinguished acute care episodes from routine care at the HC. This has not been previously investigated among the remote dwelling Aboriginal infant population in the NT. We identified respiratory, skin and gastrointestinal symptoms as the leading new problems seen at the HC. Others have shown similarly high presentation rates primarily for infectious diseases in remote HCs [11]. High rates of primary health service utilisation have also been identified among suburban Victorian infants, however the bulk of the visits were unrelated to acute illness unlike our findings [19].

A third of presentations were for routine health checks and other non-acute interventions. Community-based workers, Strong Women Workers and AHWs are ideally situated to provide much of this preventive care and health education in a culturally safe framework and potentially reduce the workload for clinical staff busy attending to the burden of acute illness, although this is not currently occurring in many remote settings.

Poor basic living conditions contribute to the burden of disease [20]. However, in an era when the nation is focused on closing the gap in under 5 mortality and health outcomes, providing better care for infants in their first year of life is a critical issue that must be targeted. Health services should be designed to provide high quality health care for infants as well as preventative education and effective interventions for known

contributors to poor infant health outcomes such as maternal and household smoking. Ideally this should commence early in the antenatal period.

Several approaches to improving health service effectiveness are being introduced across remote communities including the Healthy Under Five Kids program, designated child and family health nurse positions, and the expansion of family support workers. These programs are in their implementation phase and have not been funded to be rigorously evaluated.

We identified a high rate of hospitalisation. One third of infants were admitted to the NNU following birth. This is double the admission rate for non-Aboriginal infants in the rest of Australia [21]. More than half of the infants admitted were born preterm. The total preterm birth rate was 6% higher in these communities compared with the preterm birth rate among other Aboriginal babies in the NT [21]. Problems with the accurate estimation of gestational age due to poor maternal recall of menstrual period dates and uptake of early ultrasound, are well described in the Australian Aboriginal population [22-24]. We identified 8/42 premature LBW infants whose true gestation we could calculate based on 1<sup>st</sup> trimester ultrasound. Only one case of misclassification as premature occurred.

Excluding NNU admissions, 47% of infants had at least one hospital admission before they turned one. The high rates of admissions for respiratory infection identified in our study concur with other NT studies [25, 26].

Despite the large number of visits audited, the retrospective nature of this study limits causal inference and a number of infant records were unavailable for review. It seems likely that these few records were missing completely at random so the impact on inference is likely to be minimal. Data linkage between primary HC and hospital records was complicated by infants with multiple first and surnames and addresses; some misidentification of infants may have occurred. Finally, given the mobility of Aboriginal populations in the NT [27], infants may have presented for care at other health services or have been admitted to a hospital other than the regional hospital reviewed in this study, in which case our results would only underestimate service utilisation.



## Conclusions

Remote dwelling Aboriginal families seek health care for their infants frequently. There have been few studies that can provide comparative data with these results. These infants have extremely high rates of health service utilisation and hospitalisation representing an appalling disease burden among this population. Health centres are not staffed to provide this level of care for the under one-year population. Optimising the delivery of preventive and curative health services through targeted workforce planning and evidence-based approaches, which engage families and the broader community, should be implemented and evaluated.

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## **5.6 PAPER 5: Bar-Zeev S, Kruske S, Barclay L, Bar-Zeev N, Kildea S.**

**Adherence to Management Guidelines for Growth Faltering and Anaemia in Remote Dwelling Australian Aboriginal Infant and Barriers to Health Service Delivery. *BMC Health Services Research* 2013**

**Paper status:** In press

### **Research objectives addressed in this paper:**

- To measure clinicians' adherence to local guidelines for growth faltering and anaemia and follow up of identified problems in infants, as a measure of the quality of care.
- To identify the barriers to quality health service delivery for Aboriginal infants.
- To document the state of health among Aboriginal infants during their first year.

## **Abstract**

**Background:** Remote dwelling Aboriginal infants from northern Australia have a high burden of disease and frequently use health services. Little is known about the quality of infant care provided by remote health services. This study describes the adherence to infant guidelines for anaemia and growth faltering by remote health staff and barriers to effective service delivery in remote settings.

**Methods:** A mixed method study drew data from 24 semi-structured interviews with clinicians working in two remote communities in northern Australia and a retrospective cohort study of Aboriginal infants from these communities, born 2004–2006 (n=398). Medical records from remote health centres were audited. The main outcome measures were the period prevalence of infants with anaemia and growth faltering and management of these conditions according to local guidelines. Qualitative data assessed clinicians' perspectives on barriers to effective remote health service delivery.

**Results:** Data from 398 health centre records were analysed. Sixty-eight per cent of infants were anaemic between six and twelve months of age and 42% had documented growth faltering by one year. Analysis of the growth data by the authors however found 86% of infants experienced growth faltering over 12 months. Clinical management and treatment completion was poor for both conditions. High staff turnover, fragmented models of care and staff poorly prepared for their role were barriers perceived by clinicians' to impact upon the quality of service delivery.

**Conclusion:** Among Aboriginal infants in northern Australia, malnutrition and anaemia are common and occur early. Diagnosis of growth faltering and clinicians' adherence to management guidelines for both conditions was poor. Antiquated service delivery models, organisation of staff and rapid staff turnover contributed to poor quality of care. Service redesign, education and staff stability must be a priority to redress serious deficits in quality of care provided for these infants.

**Keywords:** Aboriginal, adherence, anaemia, Australia, barriers, growth faltering, infant, management guidelines, primary health care, remote

## Background

Health outcomes of Australian Aboriginal children are significantly worse than their non-Aboriginal counterparts [1]. These differences are manifest in two to three times higher rates of perinatal mortality, preterm birth and low birth weight [2]. The prevalence of anaemia and nutritional problems is much higher in Aboriginal children during their first years of life as is the overall burden of disease and hospitalisation rate [3-6]. Prevention of nutritional disorders during infancy is imperative as early growth and development form the foundation for health and learning throughout the rest of life [7]. Iron deficiency anaemia is the leading type of anaemia identified in remote dwelling Aboriginal children in the Northern Territory (NT) [8]. It is thought to result from low birth weight, chronic infection, delayed introduction and inadequate intake of iron-rich foods and high rates of parasite and worm infestation which cause diarrhoea, growth faltering and malabsorption [9-11]. Numerous studies have shown associations between iron deficiency anaemia and delayed psychomotor development and behavioural problems in childhood [12-15].

Most Aboriginal people in Australia live in cities and regional areas, with one quarter residing in remote communities [16]. Aboriginal people living in these communities tend to have worse health outcomes than those in urban or larger rural areas [17].

Aboriginal infants in the NT frequently use remote primary health services in their first year of life, mostly for acute illness [18-19]. Growth and anaemia monitoring are also common reasons for primary health service use [19]. Despite the frequent use of services, data describing the quality of services are limited [20-21]. We therefore aimed to measure the quality of service delivery provided to Aboriginal infants in remote health centres (RHCs) against local guidelines. Growth faltering and anaemia were selected as quality indicators given their high prevalence in remote NT communities and the importance of their management from an early age for long term health [7]. This study also sought to identify barriers to effective health service delivery in these RHCs.

This paper reports on baseline data from the '*1+1 = A Healthy Start to Life*' project. It used a participatory approach and a mixed method design to inform interventions led by health service staff to improve maternal infant care for remote dwelling families in

northern Australia. The project was developed in response to concerns voiced by Aboriginal women, policy makers and clinicians about the quality of maternal and infant health services.

### **Setting**

Study sites were RHCs in two large (population 2200–2600) remote Aboriginal communities situated around 500km from the major referral hospital in Darwin. Darwin is a small capital city with health services out of proportion for its large catchment area. It is located in the ‘Top End’ of the NT of Australia.

Within the remote communities English is typically the second or third language, unemployment common and family income among the lowest in the country [22]. Remote health centres are open during business hours with staff ‘on call’ for emergencies. Most health care is provided by registered nurses (RNs), midwives and Aboriginal Health Workers (AHWs) within the RHCs. Aboriginal health workers are felt to ‘bridge to the cultural chasm’ dividing the Indigenous and non-Indigenous ideologies, thus acting as a cultural broker as well as primary health care worker [23]. Aboriginal health workers provide ‘clinical and primary health care for individuals, families and community groups. They deal with patients, clients and visitors to hospitals and health clinics and assist in arranging, coordinating and providing health care in Aboriginal and Torres Strait Islander community health clinics’ [24].

An onsite doctor sees patients on a referral basis. Outreach paediatricians and child health nurses from Darwin visit regularly. There are no inpatient beds in the RHCs so infants requiring medical evacuation are flown to the regional hospital.

The burden of disease and the use of RHCs by infants from these communities are very high, commencing from birth and continuing throughout the first year. Twenty-one per cent of all infants born 2004–2006 were preterm and 18% were low birth weight. One third of infants were admitted to the regional hospital neonatal nursery, primarily for preterm birth, low birth weight and presumed sepsis.

Infants had a mean of 28 presentations to the RHCs per year, with half of all visits for new, acute problems. Remaining presentations were for reviews or routine health service provision such as growth monitoring and immunisation. By age one 59% of

infants were admitted to hospital at least once, most commonly for respiratory infections (47%), gastroenteritis (27%) and failure to thrive (5%). The rate of hospitalisation per infant year was 1.1 (95% CI 0.9–1.2) [19].

Anaemia and growth faltering are major child public health problems in remote NT communities [25] and thus require population-based approaches for their prevention and management. At the time of data collection the Growth Action and Assessment (GAA) program was the main health program for remote dwelling children under five years. It has since been superseded by the 'Healthy Under 5 Kids' program [26]. Growth Action and Assessment was implemented in the NT in the 1990s to address poor nutrition – one of the leading causes of morbidity in remote Aboriginal children. It was designed to tackle growth and nutritional issues using surveillance, monitoring and treatment guidelines outlined in a local Standard Treatment Manual [27] used for common infant presentations in remote practice. These guidelines are designed to be used by all remote clinicians and standardise care.

There is a high turnover and ongoing shortage of nursing and midwifery staff working in remote settings [28] and those with midwifery and child health qualifications have declined from 65% and 18%, respectively in 1995 to 29% and 11% in 2008 [29]. This is thought to result from modifications that have been made to postgraduate nurse education and the expanded choice of postgraduate courses on offer [29].

Ethics approval was obtained from the Human Research Ethics Committee of the Menzies School of Health Research, and remote community leaders. Written consent was obtained from interview participants.

## **Methods**

We used a mixed methods approach [30] integrating a retrospective cohort study and interviews with clinicians to identify barriers to high quality remote health service delivery. Data was collected between January–August 2008.

### **Retrospective cohort study**

We undertook a retrospective cohort study of all Aboriginal infants from these communities, collecting data from birth to age one. Infants born 1<sup>st</sup> January 2004 to 31<sup>st</sup> December 2006 with gestation of at least 20 weeks or birth weight of at least 400



grams and born at the regional centre hospital, in hostel accommodation, in transit to hospital or in the remote community, were included. We constructed the study cohort through manual data linkage between community birth records and medical records at the two RHCs and the regional hospital, identifying 424 eligible infants. Of these infants, 11 (2.6%) had no community or hospital record. The final cohort consisted of 413 infants; 398 of these infants had a RHC record available for review. There were 2 neonatal and 2 infant deaths in this study.

Data were collected by manually reviewing the infants' medical record at the RHCs. We collected data in Table 17 and assessed it against guidelines [27] for the identification and management of infants with anaemia and growth faltering. Health centre clinicians reported these conditions to be commonly occurring and problematic to manage.

**Table 17: Infant data collection and guidelines**

| <b>Anaemia diagnosis criteria</b>            | Haemoglobin (Hb) <110g/dL   |            |                                   |           |         |            |         |                      |          |
|--|---|------------|-----------------------------------|-----------|---------|------------|---------|----------------------|----------|
| <b>Anaemia monitoring</b>                    | Recorded Hb between 6–12 months<br>Hb at 1 <sup>st</sup> diagnosis of anaemia<br>Age and weight at 1 <sup>st</sup> diagnosis  |            |                                   |           |         |            |         |                      |          |
| <b>Treatment guidelines for anaemia</b>      | Dietary advice<br>Albendazole (parasite) treatment: given for 3 days<br>Iron treatment: type of treatment, number of intramuscular doses<br>Folate for Hb <9gm/dL<br>Follow-up Hb after 4 weeks   |            |                                   |           |         |            |         |                      |          |
| <b>Poor growth/growth faltering criteria</b> | A child is not growing well if their plotted weight does not follow the shape and direction of the centile growth curves on the growth charts or if there has been no weight increase for:<br><br><table border="0"> <thead> <tr> <th><b>Age</b></th> <th><b>Time of no weight increase</b></th> </tr> </thead> <tbody> <tr> <td>&lt;2 months</td> <td>2 weeks</td> </tr> <tr> <td>2–5 months</td> <td>1 month</td> </tr> <tr> <td>6 months to &lt;3 years</td> <td>2 months</td> </tr> </tbody> </table> | <b>Age</b> | <b>Time of no weight increase</b> | <2 months | 2 weeks | 2–5 months | 1 month | 6 months to <3 years | 2 months |
| <b>Age</b>                                   | <b>Time of no weight increase</b>   |            |                                   |           |         |            |         |                      |          |
| <2 months                                    | 2 weeks   |            |                                   |           |         |            |         |                      |          |
| 2–5 months                                   | 1 month   |            |                                   |           |         |            |         |                      |          |
| 6 months to <3 years                         | 2 months  |            |                                   |           |         |            |         |                      |          |

|  |  |
|--|--|
| <b>Growth monitoring</b>                         | Record of 'Road to Health' chart<br>Record of Growth Action and Assessment (GAA) form (used for recording of Hb, weight, height and head circumference)<br>Number and timing of GAA visits<br>Weight, height and head circumference at each GAA visit  |
| <b>Treatment guidelines for growth faltering</b> | Where growth faltering identified, intervention recorded: <ul style="list-style-type: none"> <li>• Additional growth monitoring</li> <li>• Nutritional education</li> <li>• Supplemental food for growth catch up</li> <li>• Medical checklist</li> <li>• Paediatric referral</li> <li>• District Medical Officer (DMO) referral</li> <li>• Growth Action Plan*</li> <li>• Community support services (e.g. community/early childhood programs that support child health, feeding programs, referral to family support workers)</li> <li>• Vitamin A</li> <li>• Hospitalisation for failure to thrive</li> <li>• Family meeting</li> </ul> |

\*A Growth Action Plan was designed for implementation by the clinicians to ensure timely and appropriate interventions for the infant as soon as growth faltering was detected.

### Interview data

The first author conducted 24 semi-structured interviews with clinicians who provided or managed child health services in the two remote study sites (Table 17). Seventy-one per cent of clinicians (n=17) were resident in the remote community; the remainder based in the regional centre providing outreach services. Initial purposive sampling recruited 17 clinicians with snowball sampling recruiting a further seven clinicians. Recruitment continued until data saturation had been achieved in the analysis. Interviews included core questions about the clinicians' role, experience and views of remote infant health services and barriers to service delivery.

**Table 18: Interview participants**

| <b>Place of Employment</b> | <b>Clinicians (n=24)</b>   |
|----------------------------|--|
| HC 1 (n=9)                 | District Medical Officers (n=2)<br>Remote Area Nurses (working in general roles) (n=2)<br>Remote Area Nurses (working in child health roles) (n=2)<br>Aboriginal Health Workers (n=1)<br>Managers (n=2)  |
| HC 2 (n=10)                | District Medical Officers (n=2)<br>Remote Area Nurses (working in general roles) (n=2)<br>Child Health Nurses (working in child health roles) (n=3)<br>Aboriginal Health Workers (n=1)<br>Managers (n=2) |
| Regional Centre (n=5)      | Outreach (visiting) Child Health Nurses (n=2)<br>Outreach (visiting) Paediatricians (n=3)  |

### **Data analysis**

Medical record data were entered into an Access™ (Microsoft Corporation) database, cleaned and analysed using STATA™ version 12.1 (Statcorp, College Station, Texas). Continuous data are reported as means (1 standard deviation (SD), 95% Confidence Interval (CI)) or medians (Interquartile Range (IQR)). Dichotomous data are reported as proportions. Time to event data are presented using Kaplan-Meier estimators, and p values derived using log-rank test. Z-scores based on World Health Organization (WHO) Child Growth Standards were derived using WHO published software for STATA [31].

Interviews were audio recorded with participants' consent and transcribed *verbatim*. Field notes written during and following interviews described the setting, participants' behaviours, body language and non-verbal communication. Pseudonyms were used for anonymity. The transcribed qualitative material was analysed by the first author using content analysis in ATLAS™ T.I 5.4 (Scientific Software Development GmbH, Berlin, Germany). The transcriptions were examined to identify issues and themes in the data, assigning codes to units of meaning apparent in each paragraph or sentence. Data were

then consolidated into higher-level categories and core themes identified. Frequencies evident within the core themes were then ascertained.

## **Results**

### **Anaemia**

Guidelines recommend Hb monitoring at six-monthly intervals from six months of age [27]; 85% (n=338) of infants with an available health record (n=398) had at least one recorded Hb between 6–12 months. Anaemia prevalence among all infants was 68% (n=228) (95% CI 62.6–72.7); mean Hb 97.3gm/dL at first diagnosis (SD 9.3, 95% CI 96.1–98.5) when the mean age at diagnosis was 7.6 months (SD 2.8 months, 95% CI 7.3–8.0). The proportion of infants anaemic did not vary by prematurity status (term 68.0%, preterm 68.3%; p=0.97).

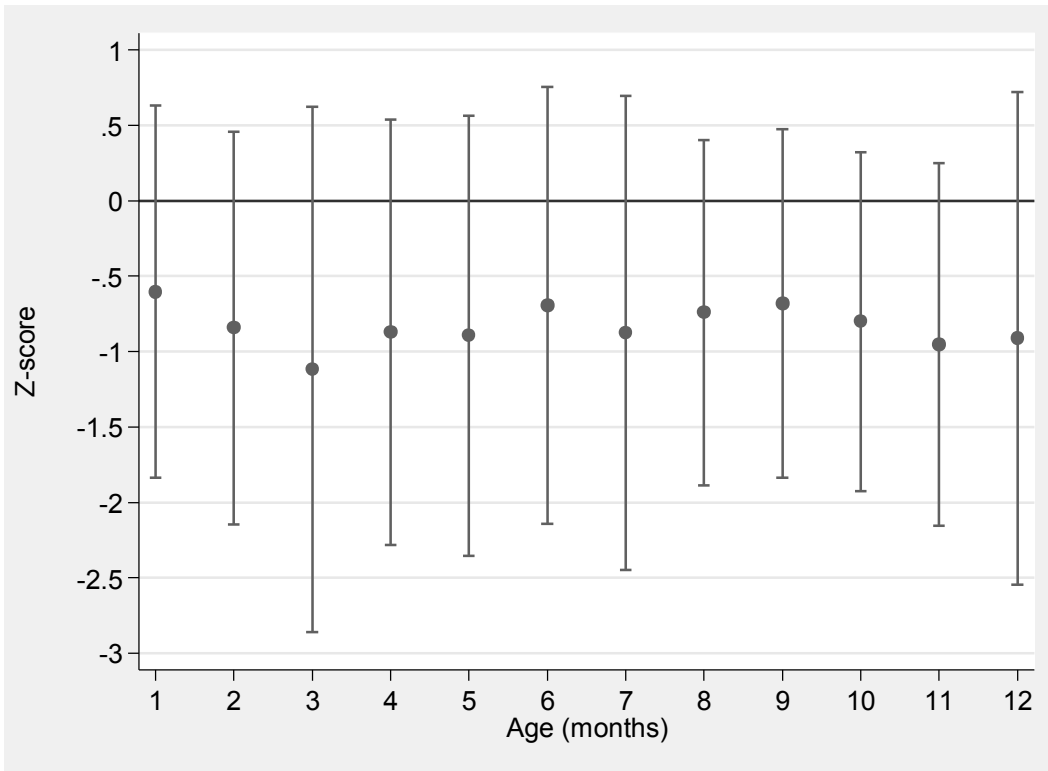
Twenty per cent of anaemic infants (n=48) had documented dietary advice; 27% (n=62) received a complete course of Albendazole supervised by a RHC staff member. One third of infants (n=68) received a completed course of iron (1–3 IM injections based on age and body weight) and 28% (n=65) did not receive any iron treatment despite having documented anaemia. A follow-up Hb was checked in 60% of anaemic infants (n=137). Less than one third (n=11/42) of infants with an Hb <9gm/dL received folate.

### **Growth faltering**

Hard copy 'Road to Health' growth charts based on international references [32] were used for growth monitoring during the study period. Guidelines recommended regular growth monitoring and immediate intervention for faltering, commencing from birth. Growth faltering was documented by clinicians in RHC records of 42% (n=167) of infants by age 1.

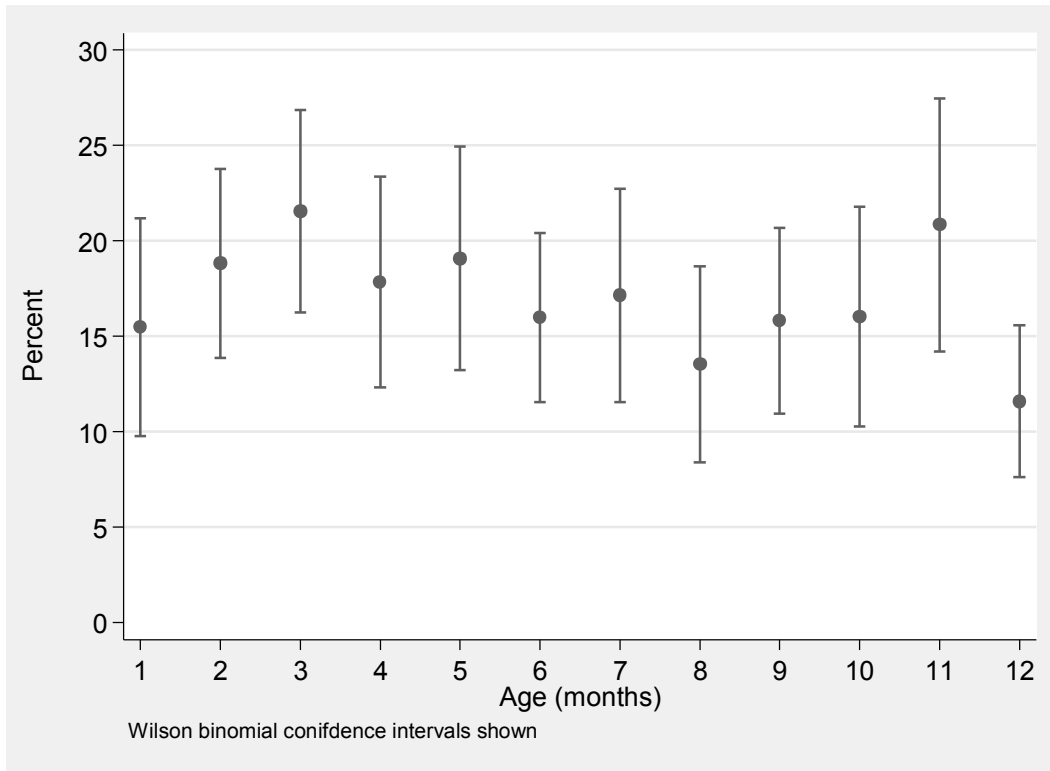
### **Z-scores**

There were 2346 monthly observations of weight recorded for 372 infants; the median number of observations per child was 5 (IQR 4 to 9). There was no evidence for a difference in mean visits by prematurity status (term 6.1, preterm 5.9; p=0.62), or by underweight (>0 episodes weight for age Z-score  $\leq$ -2 6.1, no such episodes 6.6; p=0.12). The mean weight for age Z-score by infant was -0.80 (SD 1.3) (Figure 9).



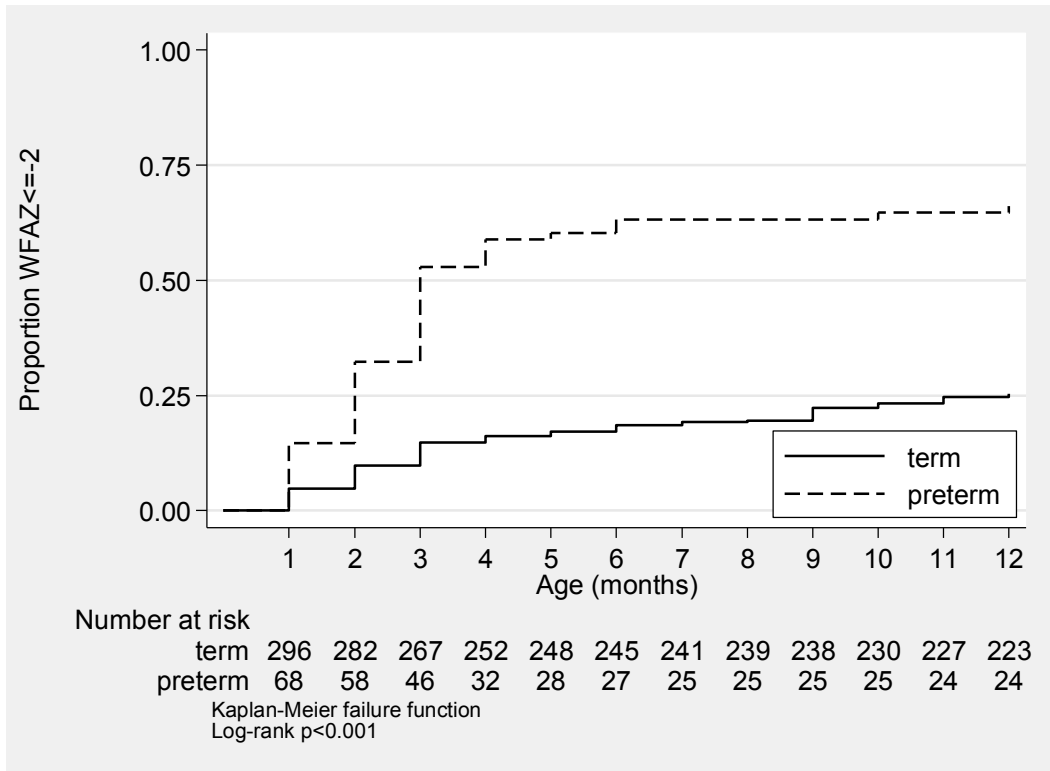
**Figure 9: Mean (SD) weight for age Z-score  $\leq -2$  by month of age**

There was no significant difference by gender. Marginal population mean (SD) prevalence of weight for age Z-score  $\leq -2$  at each monthly visit is shown in Figure 10. Among 372 infants there were 398 observations of weight for age Z-score  $\leq -2$  of which 122 ( $122/372=33\%$ ) were first episodes, with mean age at first occasion being 3.9 (SD 3.1) months.



**Figure 10: Per cent of infants with weight for age Z-score  $\leq -2$  at each month of age**

Among 296 term infants, 75 (25.3%) had at least 1 episode weight for age Z-score  $\leq -2$  among whom mean age at first episode was 4.4 (SD 3.3) months. Among 68 preterm infants, 45 (66.2%) had at least 1 episode among whom mean age at first episode was 2.9 (SD 2.2) months;  $p=0.008$  (Figure 11). For 940 observations of length among 354 infants, the mean length for age Z-score was  $-0.91$  (SD 1.6) and for 931 observations of concurrent weight and length, the mean weight for length Z-score was  $-0.21$  (SD 1.4).



**Figure 11: Proportion of infants having weight for age Z-score  $\leq -2$  at least once**

Analysis of Z-score data revealed a high proportion of infants underweight, stunted or wasted in their first year (Table 19). Authors 1 and 2 independently analysed the change in monthly Z-scores for each of 374 infants and identified growth faltering (defined as any drop in Z-score) in 322 (86%) compared to 42% in whom faltering was documented by clinicians in RHC records. Of the 374 infants with two or more recorded weights: 55 (14.7%) had no growth faltering, 167 (44.6%) had a loss of less than 1 Z-score, 126 (33.6%) lost between 1 and 2 Z-scores, 24 (6.4%) lost between 2 and 3 Z-scores and 2 (0.5%) lost greater than 3 Z-scores.

Among all infants with growth faltering (n=322), less than half received additional growth monitoring. Delivery of other interventions recommended in guidelines was often low (see Table 20) and the quality of documentation in the health record regarding the intervention and follow-up management plan was often poor and incomplete.

**Table 19: Infants who are underweight, stunted or wasted**

| <b>Anthropometric measure</b> | <b>n</b> | <b>Proportion of cohort with overall mean Z-score <math>\leq -2</math> for first year of life</b> | <b>Proportion of cohort with at least 1 episode of Z-score <math>\leq -2</math> in first year of life</b> |
|-------------------------------|----------|---|---|
| Underweight (weight for age)  | 372      | 55 (14.8%)  | 122 (32.8%)   |
| Stunted (length for age)      | 354      | 58 (16.4%)  | 97 (27.4%)  |
| Wasted (weight for length)    | 354      | 19 (5.4%)   | 65 (18.3%)  |

**Table 20: Proportion of infants with growth faltering identified by health worker who received an intervention**

| <b>Intervention</b>                   | <b>Received intervention</b> | <b>Growth faltering documented by clinician<br/>n=162</b> | <b>Growth faltering identified by this study<br/>n=322</b> |
|---------------------------------------|------------------------------|---|--|
| Extra growth monitoring               | 154                          | 95%   | 48%  |
| Nutritional advice                    | 110                          | 68%   | 34%  |
| Nutritional supplements               | 65                           | 40%   | 20%  |
| Medical checklist                     | 61                           | 38%   | 19%  |
| Referral to paediatrician             | 58                           | 36%   | 18%  |
| Referral to DMO                       | 48                           | 30%   | 15%  |
| Growth Action Plan                    | 48                           | 30%   | 15%  |
| Community support/services            | 24                           | 15%   | 7%   |
| Vitamin A/Zinc                        | 21                           | 13%   | 7%   |
| Hospitalisation for failure to thrive | 19                           | 12%   | 6%   |
| Family meeting                        | 16                           | 10%   | 5%   |

**Barriers to remote health service delivery**

Interviews were undertaken to validate and explain our quantitative findings. Analysis of interview data revealed clinicians' perspectives on barriers to health service delivery.



These were particularly related to institutional factors and staff capacity. All clinicians interviewed recognised the quality of care for these infants was suboptimal.

### **Organisational structure**

Clinicians identified poor organisation and inadequate staffing of the RHCs as significant barriers to health care delivery. Each RHC had one or occasionally two nurses designated to provide primary child health care services to the under 5 population (approximately 300–320 children, of which were 60–80 infants). One RHC provided the primary health service on a part-time basis; the other provided a full time service.

Given the high volume of acute and complex presentations in both RHCs, additional RHC staff would frequently be required to assist with clinical management of infant cases. This interfered with the ability of staff to provide continuity of care and effective follow up of infants with identified problems. For example, an infant presenting to the RHC over a number of days could be seen by a different staff member at every presentation. Rarely did infants who presented with an acute illness receive routine or overdue health assessments unless designated child health clinicians saw them. Most non-designated child health clinicians did not view growth assessment, immunisations, anaemia checks or follow-up treatment as their responsibility, as one clinician observed:

*'...the child health nurse will write (in the medical notes) 'this child needs a Hb at the next check' but the kid's seen for acute presentations 20 times in between and it's only when they get back to the well baby clinic (primary health service) that they get that Hb.'* (F1)

The high turnover of staff was also perceived to compromise continuity of health care delivery. During the eight-month data collection period, each RHC had 5–7 different nursing staff rotating through the child health services; 75% of these were on short-term contracts (2 weeks – 6 months).

### **Medical models of care**

The high burden of disease in both communities was thought to have contributed to the health service's long-standing focus on acute care and lesser value placed on preventative health care and education. This was clearly demonstrated among the

mothers of these infants, whereby 31% of mothers were identified to be smokers at their first antenatal care visit yet only 8% received any smoking cessation advice. This focus on acute care was also evident in the delivery of child health services [33].

One clinician stated:

*'We see the same kids week in week out with respiratory illness...We give them antis (antibiotics) and send them home. This is a major issue here. Yeah, I guess you know you are never going to fix these kids as we don't deal with the real problem...the preventive stuff like everyone in the house smoking all the time.'* (S3)

Linguistic and cultural barriers, including a lack of interpreters and culturally appropriate health education resources, and the complexity of family dynamics were also noted to compromise effective health service delivery.

### **Inadequate staff knowledge and skills**

Only one nurse interviewed had formal child health qualifications, two had not previously worked with children and three were working in a remote health service for the first time. The lack of child health knowledge and skills specific to the needs of Aboriginal children particularly among nursing staff were compounded by reports of inadequate orientation to the health service and a lack of familiarity with the use of guidelines and surveillance tools, such as growth monitoring charts and limited opportunities for ongoing education or mentoring and supervision by senior staff.

More than half of the RHC-based nurses interviewed did not feel competent to provide culturally appropriate health care to Aboriginal families and reported difficulties managing failure to thrive and nutritional issues. Illustrating this point, one participant noted:

*'I don't know how to challenge families about feeding issues...you know the kid isn't being fed properly but I feel like if you say this, it's just shame (public embarrassment) and they'll just think 'stuff her' and not come back.'* (L5)

### **Lack of Aboriginal staff**

Many clinicians described the lack of AHWs, senior Aboriginal women or other local Aboriginal community workers involved in the delivery of infant health care services. In

both RHCs, AHWs were predominantly working in administrative roles, despite their extensive clinical experience. Clinicians reported a steady decline in the number of AHWs and in their scope of practice. All non-Aboriginal clinicians described AHWs as imperative to effective health service delivery given their experience, relationships with local families, language and cultural and community knowledge.

Other barriers to service delivery, less frequently reported, related to the family's responsibility to attend for care when required for follow-up treatment. Families often spent time away from their home communities looking after family members in hospital in Darwin, attending funerals, ceremonies or bush holidays and did not present with their infants for care when this had been planned. Traditional Aboriginal cultural ceremonies were significant in both remote communities and mourning and funeral obligations taken seriously. These often involved families relocating to stay with family in mourning or where the ceremony was being held for extended periods of time, sometimes for up to several months.

Families were usually dependent on transport provided by the RHC to attend follow-up appointments, as there was no public transport available. At times, a lack of drivers or vehicles meant that families were not brought to the RHC when required. On other occasions, drivers or clinicians themselves would present numerous times to the family's home but they would either not be there or refuse to be transported to the RHC because the timing was inconvenient. Clinicians also reported visiting families who were known to be 'poor attendees' at their home to 'encourage' their attendance. These strategies fail to increase the capacity of families to take responsibility for the health of their children though clinicians often reported the dilemma of not 'chasing up families' versus the rights of the child to receive health care.

## **Discussion**

Access to quality primary health care services is a determinant of good health [34]. The findings from this study show remote NT health services are not providing effective management of anaemia nor adequate identification of growth faltering for Aboriginal infants.

Growth faltering and anaemia prevalence was higher than previously documented [20-21, 35]. Growth faltering was documented by clinicians in 42% of infants, however by a

definition of any reduction in Z-score over time we identified over twice that number. Whether seen as point prevalence at each monthly visit, or when examined as an overall mean low Z-score over all visits per child we detected a higher proportion of infants underweight and stunted than the NT GAA survey during the same period (12% and 7% respectively) [35], and the proportion of children with at least one episode was higher still. The NT GAA cross-sectional survey reports measurements per child at a single timepoint, whereas we followed the measurement of the cohort over 12 months. The fact that in our cohort the proportion with any episode of underweight is higher than the proportion with overall mean underweight over 12 months may be accounted for in part by infants who falter several months into their first year and in part may suggest that some infants who become malnourished may improve. However, overall prevalence changes very little by month.

The rate of first episode underweight in the cohort was 32.8%, and growth faltering was found in 86% of infants. The number of observation visits did not vary by prematurity or underweight, but only a small proportion of children had 12 GAA monthly visits. Excluding missed visits from person time observed gives an incidence of 820 per 1000 infant years, but including missed visits in observation (and assuming no underweight episodes in the interval censored observations) gives an incidence of 421 per 1000 infant years. We have shown that among Aboriginal infants in the Top End malnutrition is common, occurs early and is persistent over the first year of life.

Anaemia was identified in 68% of infants but only one third received a completed course of treatment for this. Less than one third of all anaemic infants failed to receive any treatment despite having this condition documented in the health record. Anaemia associated with preterm birth is a common problem worldwide [36]. This has substantial clinical implications including the interference with normal growth leading to subsequent growth faltering [36] and recovery processes for respiratory diseases and bacterial infections [37], all highly prevalent problems in remote Aboriginal infants in Australia's Top End [38]. However, in this study we demonstrated that anaemia was not associated with prematurity. Although we found a significantly higher and earlier incidence of WFAZ  $\leq -2$  among preterm infants it should be borne in mind appropriate gestational age correction may not have been routinely done by health workers.

Poor identification and management of infant health problems was contributed to by staff not receiving adequate education, supervision, orientation to remote health services, lack of familiarity with local guidelines and inadequate skills in accurately or systematically plotting and interpreting growth. Electronic systems are now being used in many RHCs, where computer programs plot infants' growth against international standards. This will lessen the risk human error in the plotting of measurements.

Remote dwelling Aboriginal infants access RHCs frequently from an early age [18-19] and clinicians were overburdened by the volume and complexity of presentations. This compromised their ability to provide good care. Poor organisation and utilisation of existing staff was identified, such the AHWs in these settings being used in administrative roles despite their experience and knowledge.

Lack of continuity, which in this study arose from high staff turnover, staff being moved between different health program areas and multiple (or absent) handovers of care, will increase errors and jeopardise safety [39]. Continuity of carer is a critical component of primary health care known to improve the quality of service delivery [40]. Studies indicate that continuity of carer at the primary care level reduces hospital admissions, improves compliance with treatment, increases preventive care and improves relationships between clinician and patient [41-42]. Maintaining skilled and knowledgeable continuity of carer can be challenging in this context given the high staff turnover and difficulties retaining staff in remote communities [43] but should be a priority.

Poor follow up of infants with identified health problem in other remote health services across Australia has also been shown by Baillie et al. (2008) [20] reflecting the inability of current health systems to adequately provide for these Aboriginal populations. Low rates of adherence to local guidelines for the delivery of antenatal care and follow up of highly prevalent problems such as sexually transmitted infections, smoking and anaemia were also found in these two remote communities and the barriers to providing care similar to those described in this study [33].

There are a number of strategies that could help to improve the quality of care in these remote health services (see Table 21) such as service redesign that includes appropriate staffing based on service utilisation patterns and actual workload [44-45]

with community-based health service delivery by community workers (CWs) [46]. This might also reduce the high work load in RHCs, allowing RHC-based clinicians to concentrate on providing acute care.

**Table 21: Key strategies to improve the quality of remote infant health care**

|   |   |
|---|---|
| <p><b>Service organisation and delivery</b></p> | <ul style="list-style-type: none"> <li>• Implement a culturally appropriate model of service delivery based on community development principals and continuity of care.</li> <li>• Provide flexibility in service delivery: times/location, home visiting, community-based care</li> <li>• Increase delivery of community-based health care interventions.</li> </ul>   |
| <p><b>Workforce</b></p>                         | <ul style="list-style-type: none"> <li>• Staffing for health services based on patterns of service use, workload and community health care needs.</li> <li>• Scale up of designated child health nurses and community-based family support workers.</li> <li>• Ensure effective integration and increase leadership of AHW staff in the health service.</li> </ul>  |
| <p><b>Education and training</b></p>            | <ul style="list-style-type: none"> <li>• Mandatory cultural security training undertaken by all clinicians prior to commencement of employment in remote communities. Inclusion of a component on Aboriginal child rearing practices.</li> <li>• Introduction of a minimum set of core competencies in child health for all clinicians that are assessed on an annual basis.</li> <li>• Ensure clinicians working with children are appropriately qualified to do so or be working towards obtaining a child health qualification.</li> <li>• Provide clinicians with opportunities to undertake distance education modules to build skills and knowledge directly relevant to remote area practice.</li> <li>• Ensure all clinicians have access to designated ‘specialist’ mentors or preceptors within and external to their workplace that can provide mentoring and opportunities for knowledge and skills refresher training in the workplace.</li> </ul> |

|  |  |
|--|--|
|  | <ul style="list-style-type: none"> <li>• Ensure AHWs and other community workers have a larger role in health education and health promotion activities or community-based interventions, such as for growth faltering.</li> </ul>   |
| <p><b>Clinical governance and leadership</b></p> | <ul style="list-style-type: none"> <li>• Management to ensure all new and existing clinicians are orientated to the health service and trained in the use of the local guidelines, primary care manuals, referral practices and documentation. Ensure regular refresher training on use of guidelines and patient information systems.</li> <li>• Regular supervision of health care practice and auditing of documentation.</li> <li>• Establish key targets for health outcomes and service delivery performance specific to the needs of individual health facilities.</li> <li>• Implementation of local systems for regular monitoring and evaluation of child health outcomes and health system performance with action plan for facilitating improvements.</li> </ul> |

Evidence supports the need for early intervention in the treatment of growth and nutritional conditions. Community-based interventions however, involving carers and other CWs are effective in addressing underlying issues and prevent repeated episodes [47-48] and need to be considered as part of health service planning for this population. The use of carefully chosen, appropriately trained and well-supported CWs for the delivery of health education, basic primary health care and to provide linkages to health services has been a successful strategy in many under-resourced settings [46]. In this study, we identified very poor engagement of clinicians with carers to address growth and nutritional issues and absence of community-based services.

There is an urgent need for increased child health skills and knowledge with most nurses lacking qualifications or experience, despite working with a population who have among the poorest child health outcomes in Australia. In other Australian settings, unqualified staff would not provide this care. Over the past decade, there have been increased educational opportunities for RNs working in remote settings [49]. However,

only 5% of the nurses who work in very remote Australian health services have specific skills and qualifications for their advanced practice role [29]. A lack of financial support to undertake further education, high workloads and on call hours makes continuing education difficult in this setting.

Cultural competency in health delivery can improve outcomes for Aboriginal mothers and infants [50-51] but attention to this was also absent. Further, understanding of child rearing practices also need to be available so any differences in parenting behaviours and values are incorporated into health messages.

Much of our data collection occurred during the NT National Emergency Response (also referred to as 'the NT intervention'). This was a legislative response introduced by Australia's federal government to tackle reports of sexual abuse and neglect of children in Aboriginal communities across the NT which saw changes made to the provision of welfare benefits, law enforcement, land tenure and restrictions on alcohol use [52]. A roll-out of child health checks and follow up of primary health and specialist services were also introduced into remote communities; however as our data collection period ceased at the end of the 1<sup>st</sup> year of life for infants born 2004–2006, few of the infants in our study were part of these checks. Further government funding was provided to remote communities to expand primary health service delivery [53]. A number of new approaches are now underway in remote NT communities to improve child health services and improve quality of care including a new evidence-based health care delivery program targeting children under five (Healthy Kids Under 5 Program), designated qualified Child and Family Health Nurses who will provide community-based care thus increasing flexibility and access to services and increasing the numbers of community-based family support workers. Also a newly developed and Indigenous-focused Graduate Diploma in Child and Family Health is now offered by the local university, by distance learning. The quality of infant health care in our study sites following the NT intervention has recently been evaluated by the 1+1 study team with the results expected for publication in the coming year.

Following our data collection, many RHCs implemented continuous quality improvement strategies to strengthen primary health care services. These quality improvement strategies included monitoring of health performance and outcome



indicators and providing feedback to clinicians to improve health care accountability [54]. The measures used here to assess the quality of infant health service delivery were developed as part of a broader set of indicators specifically for remote dwelling Aboriginal maternal and infant populations [55-56]. Regular monitoring and evaluation using such indicators can serve as a useful way of RHCs assessing health outcomes, their own service delivery performance and taking accountability for system performance. The findings of this study have been reported to Local Reference Groups in the communities and to senior policy and clinicians in the NT as part of the participatory action research study design and have contributed to health system improvements.

### **Limitations**

In the NT, Aboriginal children and their families are highly mobile [57] and it is possible that the infants may have presented for additional health care at other RHCs not reviewed as part of this study and this may bias our results. Preventive health care is often opportunistic in RHCs and some infants may have had their haemoglobin checked by a clinician if they presented at 5 months and anaemia treatment commenced at that visit. Our data collection did not capture these infants who may have had this care at an earlier date.

As our growth data were retrospectively collected from routine GAA visits forms as part of the remote health records we were unable to reliably determine whether age was corrected for gestational age among preterm infants. We suspect that correction was not always made, since the GAA program encourages health centre visits at each month of life following birth, and this may falsely inflate the rate of underweight. More non-GAA visits are often scheduled for preterm infants, but number of GAA visits did not differ by prematurity.

The protective effect of breastfeeding against infection [58-59] and growth faltering [60] is well founded. In this study we were unable to collect reliable breastfeeding data using the RHC records to examine for associations between growth faltering and breastfeeding. Breastfeeding status was not routinely documented in health centre records as part of health assessments nor was it recorded on the GAA form. Limited breastfeeding data was obtained from hospital discharge records where we found 88% of infants' breastfed on discharge. This is comparable with other data for Indigenous

and non-Indigenous infants across Australia during the same time period [61]. As part of the Healthy Under 5 Kids Program that has been implemented since the data collection in this study, information on breastfeeding is now recorded on every structured health assessment used from birth to age two [62].

## **Conclusions**

Australian Aboriginal infants have worse health outcomes than non-Indigenous infants and care provided for anaemia and growth faltering is of inadequate standard. These conditions are preventable, occur too frequently and are poorly treated. Service design, lack of continuity of carer and staffing organisation and capacity are contributing factors. These must be urgently addressed to reduce the unacceptably high disparities in health outcomes for Aboriginal infants.

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# 6 DISCUSSION

## 6.1 Introduction

This chapter revisits the objectives of this study and overviews the results as a complete linked body of work. The discussion presents a summary of the major findings in each of the papers, addressing the significance of these findings and synthesises these to answer the research objectives.

The primary goal of this study was to investigate the quality of MIH services and their use at the primary and referral level by remote dwelling Aboriginal mothers and their infants in the Top End of Australia. The secondary aim was to document the burden of disease in this population and to identify the barriers to quality health service delivery for remote dwelling Aboriginal mothers and infants.

Specific objectives for this study were to:

- Measure clinicians' adherence to local guidelines for ANC and the follow up of identified problems, as a measure of the quality of care.
- Measure clinicians' adherence to local guidelines for growth faltering and anaemia and follow up of identified problems in infants, as a measure of the quality of care.
- Identify the barriers to quality health service delivery for Aboriginal mothers and infants.
- Describe the patterns of health service utilisation by Aboriginal mothers at the RHC and the regional hospital during pregnancy, birth and the postpartum period.
- Describe the patterns of health service utilisation by Aboriginal infants at the RHC and the regional hospital during their first year.
- Document the burden of disease among Aboriginal women during their pregnancy, birth and the postpartum period.
- Document the burden of disease among Aboriginal infants during their first year.

The chapter also presents limitations followed by recommendations arising from this study and suggestions for future research.

## 6.2 Overview of Methodology

A situational analysis methodology that incorporated a uniquely designed framework for the assessment of MIH services across the continuum of care was developed and successfully implemented in this study. This framework comprised four distinct but interdigitating components (key stakeholder interviews, participant observation of health care practice, retrospective cohort study and patient journey modelling).

## 6.3 Main Findings

Paper 1: (Use of maternal health services by remote dwelling Aboriginal women in northern Australia and their disease burden. Bar-Zeev S, Barclay L, Kruske S, Bar-Zeev N, Yu G, Kildea S. 2013. *Birth: Issues in Perinatal Care* (In press) [1]). This paper reported a high level of maternal health service use at the HCs and hospital, which typically commenced in the second trimester and continued throughout pregnancy, birth and the postpartum period. The high level of service use reflects the willingness of women to engage with health services despite the multiple barriers to accessing care that were outlined in Chapter 1. It also validates the experience of clinicians distressed by taxing and poorly organised workloads when trying to provide care to Aboriginal families.

Aboriginal women experienced high levels of pre-existing medical and pregnancy related complications and hospital admissions. This confirms the disproportionate burden of disease in pregnancy and childbirth and newly identifies this throughout the first six months postpartum [1]. Anaemia, UTIs and preterm birth were the most common pregnancy related complications, with prevalence rates similar to those seen in some developing countries [2-4]. Multiple risk factors for poor maternal and infant outcomes were identified. These included smoking [5], untreated UTIs [6], STIs [7], anaemia [8] and confirmed GBS colonisation [9]. Interventions to ameliorate these risk factors should be a part of comprehensive and high quality care, for example provision of support for smoking cessation [5], or antibiotics in labour for GBS [9].

Paper 2: (Bar-Zeev S, Barclay L, Kruske S, Kildea S. Factors affecting the quality of antenatal care provided to remote dwelling Aboriginal women in northern Australia. *Midwifery* 2013 (In press) [10]). This paper reports an extension of the work reported

in Paper 1 [1] by examining the quality of service delivery during the AN period. In spite of the frequency of AN visits reported in Paper 1 [1], there was generally poor adherence to local guidelines for follow up of the abnormal clinical findings such as anaemia, UTIs and STIs. Previous studies have shown that inadequate ANC, that includes failure by health staff to provide routine screening or treatment for known risk factors and complications as demonstrated in this research, contributes to potentially avoidable, poor maternal and infant outcomes including death [11-12].

Poor service organisation impacted on quality of service delivery. Inadequate and frequent turnover of staff in remote health services, absence of good clinical governance and a lack of continuity, poor communication and coordination between levels of the health service were also problematic. Alarming, in the remote setting the quality of service delivery was also compromised by clinicians' attitudes, which resulted in selective delivery of care particularly in relation to counselling on smoking and alcohol use during pregnancy.

Paper 3: (Bar-Zeev S, Barclay L, Farrington C, Kildea S. From hospital to home: The quality and safety of a postnatal discharge system used by remote dwelling Aboriginal mothers and infants in the top end of Australia. *Midwifery* 2012; 28(3): 366-73 [13]). Investigation revealed the same problems of poor service coordination occurring in the postpartum period. In particular it highlighted dangerous discontinuities between hospital discharge to care reception at the RHC. Hospital discharge marked a serious disjunction between the services, facilities, providers and information records. There was a lack of accountability for ensuring the timely and accurate handover of care from the hospital to the remote health service. This was demonstrated in the case study whereby a woman requiring ongoing medical care and follow up was discharged from hospital to her home community without any handover and plans put in place with the HC for the woman to receive ongoing care [13].

Absence of clinical communication left remote caregivers without the information they need to provide safe and high quality care to mothers and infants. Underlying these systemic breakdowns was a lack of clinical governance and leadership. The failure of the health system to provide appropriate and timely care resulted in mothers and infant not receiving treatment and follow up of complications or test results and failure to

have medication regimes implemented [13]. This may explain, in part, the reason for the unacceptably high levels of postpartum complications identified in Paper 1 [1].

Paper 4: (Bar-Zeev S, Kruske S, Barclay L, Bar-Zeev N, Carapetis J, Kildea S. Use of health services by remote dwelling Aboriginal infants in tropical northern Australia: A retrospective cohort study. *BMC Pediatrics* 2012; 28: 12–19 [14]). This paper identified very high service use by infants at the RHC (mean 28 presentations per year, 95% CI 26.4–30.0) and in hospital, with 59% of infants having been admitted to hospital at least once by age one [14]. This service use commenced early in life and continues throughout the first year. Similar to the findings in Paper 1 [1], the high service use reflects willingness by families to access services in spite of barriers [15] and contradicts the anecdotal and published evidence around lower health service utilisation by Aboriginal people [16]. The high use of services demonstrates the appalling burden of disease among these infants and the inability of the system to respond effectively. Indeed, the majority of visits were for new, acute problems and there was a high rate of hospitalisation, both to the neonatal nursery at birth and for other admissions throughout infancy.

Paper 5: (Bar-Zeev S, Kruske S, Barclay L, Bar-Zeev N, Kildea S. Adherence to management guidelines for growth faltering and anaemia in remote dwelling Australian Aboriginal infants and barriers to health service delivery. *BMC Health Services Research* 2013 (In press) [17]). This paper presents findings from an examination of the quality of infant health service delivery at the RHC, focusing particularly on growth faltering and anaemia. These chronic conditions were chosen as the focus as they are highly prevalent and both provide ample opportunity for intervention so are good measures of quality of care. Comparable to the findings in Papers 1 [1] and 2 [10], despite high use of health services, there was poor follow up of these highly prevalent conditions. Extremely poor identification of growth faltering occurred with less than half of all infants having growth faltering accurately documented by remote clinicians and therefore failing to receive appropriate intervention [17]. When care was provided, management was heavily focused on providing medical treatment with little attention given to preventive health care or education. There was minimal engagement of community-based services and under-utilisation of Aboriginal workers in the care of these infants. The absence of the latter two is noteworthy since both are known to be

effective for the management of growth faltering in this context [18-19]. Poor service design, lack of continuity of care and carer, lack of appropriate clinical skills and absence of cultural competence were contributing factors to the poor quality of care provided.

The papers summarised above identify key features of the quality and use of remote and hospital health services in the Top End of Australia by remote dwelling Aboriginal mothers and infants. When analysed, a number of consistent core themes underpin all of these. These were:

1. The organisation, planning and staffing of services
2. Models of service delivery
3. The lack of continuity of care
4. Inadequate clinician skills and knowledge
5. Absence of cultural competence.

The following section will discuss these themes in greater detail.

### **6.3.1 Service organisation**

Poor health service organisation impaired the quality of care delivered to women and infants. In particular, the lack of an overarching system of clinical governance contributed to poor coordination, integration and cooperation between staff and service sites. There was a lack of engagement of Aboriginal workers or community-based services and inadequate or poorly used staffing ultimately resulting in dangerous discontinuities of care for patients and ineffective health service delivery.

This confirms previous studies and reports that have identified ineffective health services provided to Aboriginal women and infants in the NT [20-27] but adds to this body of work by strengthening the evidence base around how services are actually used, patterns of service use and the deficiencies in service delivery across the continuum of care and health care sites.

### **6.3.2 Lack of continuity**

Maternal and infant health services were highly fragmented with women and infants experiencing multiple discontinuities in care across the health system.

Poor continuity of care during the AN and PN periods in the RHCs was exacerbated by high staff turnover and poor organisation of staff. However, the most frequent discontinuities in care occurred at the point of transfer between care providers from the remote community to the regional centre for birth and back again. Up to seven individual discontinuities were identified during this period resulting in women having their maternity care provided by multiple clinicians across the health services. At the hospital these care providers were mostly unknown to the woman.

Continuity of care is linked to quality of care and without continuity it is improbable that care will be safe, patient-focused, cost-effective or clinically effective. The breakdown of continuity of care causes duplication and error, putting patients at serious risk [28-29].

The lack of continuity in maternal health services resulted in numerous consequences. These included miscommunication or absent communication among staff, lack of collaboration in service planning, inadequate transfer of information to different health care providers, duplication of clinical services and non-delivery of required care to patients [10, 13]. Similar fragmentation of care was observed at RHCs for infants during their first year of life [14]. There was inconsistent care and absence of continuity from nurses required to provide child health services. These inconsistencies were a result of poor staff organisation, lack of skill, high turnover of staff and also ineffective systems for transfer [14]. Frequent turnover of staff in remote communities often results from job dissatisfaction, stress, 'culture shock' and 'gap filling' by management with short-term contracts [30]. This reduces the quality of care provided to families from these communities. The high turnover of staff is also costly to health services and negatively affects the communities themselves, creating distrust of the system and the health care providers [30].

The tracking and transfer of women and infants across levels of the health system, particularly at the point of discharge from hospital, was poor [13]. Some hospitals across Australia with large populations of remote dwelling patients have attempted to redress this deficiency by appointing a discharge planner whose role has proved vital to information continuity. This has resulted in fewer discontinuities in care provision. This process however has not been used in maternity services [29].

The lack of strong referral linkages compromised the quality and effectiveness of MIH services in this study and created situations that were dangerous for clients of the service [13]. Strong links between the remote and regional services are vital to ensure that families do not 'disappear' between maternity services and child health services. When care is delivered not only across sites but separated in a small setting, such as a HC, effective and efficient care continuity and co-ordination is critical for smooth transition from one service to the other [29, 31-33].

### **6.3.3 Models of service delivery**

There was a lack of flexibility in service delivery for Aboriginal mothers and infants. Services were largely constructed around a Western, acute care model with care delivered predominantly from the health facility. There was little community participation or engagement with community-based services in any of the health services [10, 13, 17]. This ignored the Aboriginal construct of health and wellbeing [34-35] and failed to incorporate Aboriginal knowledge into care practices [36-37]. Aboriginal women themselves from remote communities have long been aware of these problems and voiced their concerns in numerous reports and maternity service reviews, which in turn have called for changes to existing systems [21-24, 38-39].

Part-time MIH services were provided in one remote community despite a high burden of disease identified in this population [10] and a heavy caseload of MIH clients. This meant women were sometimes turned away from the AN clinic if they attended at the wrong time or on the wrong day even if they had travelled in from remote outstations for the visit. In the same community, 'routine' child health services were also provided part-time and infants presenting with an acute illness were typically seen by a different health care provider to the one providing the 'routine' child health services.

Similarly if a woman presented to the HC with a non-pregnancy related problem, they would be seen by clinicians other than the midwife or DMO who would typically provide their pregnancy care. There was little professional responsibility or accountability by non-midwives or CHNs for managing pregnancy or non-acute infant health issues, such as anaemia. The management of these problems was often left by other clinicians until the woman returned for ANC or the infant returned to the CHN for follow up.

The health system provided women with little choice or control over where they were to give birth, an issue of great cultural significance that has been well described [22, 37-38, 40-44]. In this study, 10% of births occurred outside the hospital. This finding is consistent with other research [22, 38, 45] and is significantly higher than the out-of-hospital birth rate for non-Aboriginal women of 0.9% (2629/294,540) [46] and represents a risk ratio of 11.4 (95% CI 8.6–15.2;  $p < 0.01$ ). Close to 40% of the births that occurred outside of a hospital setting in this study were preterm, representing unplanned community births [14]. The remainder however could have been due to avoidance of care with the health service, as demonstrated in other studies of Aboriginal women [22, 38], signifying poor cultural safety and flexibility in the model of service delivery.

#### **6.3.4 Service planning**

Health centres did not have sufficient staffing or resources to provide high quality health care services required for communities of this size with such high levels of disease and service use. It should be borne in mind that among the national principles for investment in remote communities in the COAG National Indigenous Reform Agreement [47] the consensus was that:

‘Remote Indigenous communities and remote communities with significant Indigenous populations are entitled to standards of services and infrastructure broadly comparable with that in non-Indigenous communities of similar size, location and need elsewhere in Australia’ [47, p28].

Such standards of services and infrastructure were not apparent in this study.

Staffing for MIH in RHCs has not traditionally been based on local service population estimates, patterns of service use or population mobility [personal communication – HC Manager, Community A 2008]. Mobility of Aboriginal populations adds complexity to the provision of continuity of care and impacts upon the demands for primary health care services. There is a frequent need to service a population that exceeds that the usual resident population [48-49]. Determination of staffing levels and resources for MIH services needs to take into account the local service population, which includes visitors or temporary residents in the community who use the HC, as well as local



patterns of service use [1, 10, 14], birth counts [49] and the burden of disease in the community [1, 14]. There are however inherent difficulties in estimating a reliable and accurate service population in these communities since populations fluctuate enormously throughout the year and 'local' population data is recorded and interpreted in different ways. Additionally, a lack of service usage monitoring and reporting at the time of the study also compounded the difficulties estimating an accurate service population.

To ascertain the accuracy of birth counts in the two study communities a comparison of the live birth counts was made using three data sources: the CBRs, NT Midwives Data Collection (NTMC) and the NT birth registrations. This work was undertaken by an epidemiologist who was also a co-researcher on the *1+1* study, a demographer and myself [49]. In both communities for 2004–2006, community birth counts were higher than birth registrations and NTMC counts. Also, birth registrations were higher than NTMC counts in both communities. Staffing for MIH services should be calculated on this basis whilst also taking into consideration service usage patterns.

For Community A, there were 14 (7%) more community live births than birth registrations and 32 (19%) more community births than NTMC counts. For Community B, local records showed 22 (10%) more community births than birth registrations and 36 (17%) more community births than in the NTMC. Most of these differences concerned live births to Aboriginal mothers. In Community A, there were 33 more live births to Aboriginal mothers in community records than in the NTMC (a difference of 20%). For Community B, the difference for Aboriginal mothers was 38 live births (20%). The counts of live births to non-Aboriginal mothers in both communities were almost the same in the CBR and the NTMC. These results imply a need for MIH services ranging from 57–68 additional infants and their mothers (depending on the data source) in Community A and from 69–81 infants and their mothers in Community B [49].

Staff from both communities indicated that the CBRs included data on infants who were born to visitors of the communities. In Community A, staff agreed that 16 infants from were born to visitors, of whom eight were born to non-Aboriginal mothers. In Community B, staff identified 30 infants born to visitors. Of these, 18 were born to non-

Aboriginal mothers. Non-Aboriginal mothers were typically working in the communities, and/or were partners of workers in the community, or they had 'local' Aboriginal partners. Non-local Aboriginal mothers were those who were visiting the community.

Even so, a number of the Aboriginal parents considered to be visitors were at the same time deemed to 'belong' to the community because of marriage and family relationships. Although these families were absent from the community at different times and for varying periods, their infants were considered to have a connection with the community, were recorded in the local records and were known to utilise the HC's services from time to time. Similarly, other infants whose parents were born in the community but lived in Darwin or elsewhere and only visited the community once or twice a year were also considered to have a primary connection with the community. Families such as these were reported to split their time between various remote communities and to also use other HCs [49].

The birth registrations and MDC are the main sources for birth counts in the NT and underestimate the number of births at the community level. These differences in the birth counts have implications for staffing, resource and infrastructure planning within remote health services that are not currently addressed. In remote Australia, service providers often fail to respond to the fluctuating service demands resulting from periods of seasonal Aboriginal mobility due to inflexible funding structures and policies that do not acknowledge the diversity of the Aboriginal population [50]. Service providers in this study identified the vast amounts of unacknowledged time that was spent obtaining medical records from other health services in order to provide care for transient populations of mothers and infants [10]. They also faced difficulty providing continuity of care, follow-up treatment and post-care monitoring, which perpetuates the gaps in quality of care delivery for remote dwelling families.

### **6.3.5 Organisation of staffing**

In the RHCs, as in many rural and remote areas of Australia, midwives provided both midwifery care and acute nursing care [44]. This limited their time to work exclusively in midwifery and provide comprehensive, holistic care and timely follow up for women. Midwives were also underutilised in their role in remote communities. Midwifery care

was heavily focused on performing the physical aspects of AN checks within the HC setting. This did not include adequate preventive care antenatally or postnatally and failed to maximise opportunities for women to improve their health and socially and psychologically prepare for parenthood. The substantial administrative burden involved in the organisation and planning of hospital visits, transfers and follow up of test results and discharge paperwork also encroached significantly on time available for midwives to provide midwifery care. Much of this non-clinical work could be delegated to administrative staff.

There is a clear need for a shift to be made away from a solely 'acute care' biophysical model of providing midwifery or child health care in RHCs to employ a community development approach that strengthens 'wellness' and resilience. In large remote communities there is a great need to see midwives and CHNs employed in dedicated positions where they can provide continuity of care and work in their full scope of practice, work together effectively with community-based workers and provide home visiting and education in community settings. A study into the midwifery workforce in Australia found that one of the leading reasons for midwives leaving the profession was due to their inability to work in their full scope of practice [51-52], particularly in rural and remote areas. Thus, improving the utilisation and scope of the midwifery role in these areas could help to reduce staff turnover, greater work satisfaction among midwives and result in more effective care delivery.

Aboriginal Health Workers were underrepresented and underutilised in the health services. They were there to 'assist' with tasks, usually administrative and menial, directed at them by non-Aboriginal clinicians rather than to work in their own capacity and fulfil their own professional potential. Aboriginal representation and solid leadership at all levels of the health system is essential to the successful delivery of these health services and engagement of community members. Given the range of organisations involved in health service delivery it is crucial for all groups to provide these services together in coordinated way that best addresses the needs of Aboriginal people [53].

### **6.3.6 Inadequate clinician skills, knowledge and cultural competence**

Nursing and midwifery staff employed in the RHC and interviewed in this study were not adequately prepared for their role, frequently lacking cultural competence or the clinical skills required to provide optimal care. This represents no improvement from previously identified problems in hospital and remote health services [22, 35, 54-55]. Child health staff were often inadequately skilled for a role, which in other parts of Australia would only be provided by specifically qualified staff [56].

There is urgent need to consider the minimum skill set required for staff working in remote communities who are caring for a population who have among the worst health outcomes in the country. The lack of appropriate skills by health staff also contributes to ineffective service delivery and at times 'over servicing' of clients. This was demonstrated with the high rates of presentations to the health services for ANC and yet poor quality of care delivery, particularly for follow up of medical conditions such as for anaemia, UTIs and STIs [10]. Similarly for infants, high rates of service presentation were identified and yet there was poor quality of care for growth faltering and anaemia [17].

Clinicians' attitudes and beliefs influenced the quality and type of care women received. This is consistent with previous research in the Top End [24]. Some clinicians made selective decisions around providing or withholding information and care from women that they felt was either not in the woman's interest or was a threat to the clinician/patient relationship [10].

The impact of this type of decision-making by clinicians on mothers and their infants is substantial and can be demonstrated in the example of smoking during the AN period. Almost a third (31%) of women were identified as smokers at the first AN visit, but less than 10% were provided smoking cessation advice. Whilst there was a lack of culturally appropriate materials for this purpose at the time, best practice guidelines, which include verbally addressing smoking cessation, were available to all health staff [57]. Smoking prevention among pregnant Indigenous women is known to be 'the single most effective short-term intervention to improve Indigenous perinatal outcomes' [58, p476]. A pregnant Indigenous woman who smokes has a twofold risk of a LBW newborn, and a 30% increased risk of prematurity [59]. Low birth weight and preterm

birth were highly prevalent in this study [14]. The smoking cessation example reinforces inadequacies of health service delivery that are not only poorly dealing with existing problems but directly contribute and exacerbate them and deny women power and control in their pregnancy care and outcomes.

It is critical that health service managers, planners and clinicians understand the ineffectiveness of the way services are delivered at a health systems level in remote communities and across health sites, particularly given the added complexity, administrative burden and time involved with the transfer of care across settings. The health of Aboriginal people from remote communities ultimately needs to be addressed through improving the underlying determinants of health [60]. Health services however also provide an important role in providing effective preventive and curative health care. They have an obligation to do so using minimum acceptable standards of practice not evident in this study.

Since this study, some progress has been made towards addressing the serious inequities in care delivery and improving outcomes for women and their infants through a number of health system changes outlined in Section 6.4 below. The organisation of services however, improving service linkages, effective use staffing and quality of care at the primary and referral levels, must continue to be targeted by health care planners and considered a priority. Findings regarding the organisation, planning and staffing of services are contrary to the evidence on what are known to be effective models of service delivery for Aboriginal mothers and infants [61-82]. This disparity between evidence and practice must urgently be acknowledged and redressed by health care planners.

## **6.4 Significance of Findings**

This is the only study to follow a cohort of remote dwelling Australian Aboriginal mothers and their infants from pregnancy through birth and the postpartum period. It recorded their infant's progress through the first year and assessed their use of health services and the quality of service delivery.

Access to, and use of, quality MIH health services use is associated with improved outcomes for mothers and their infants [83]. Given that Aboriginal mothers and infants

have significantly worse health outcomes, compared with their non-Aboriginal counterparts, investigating the use and quality of health services provided to this population is of critical importance for future service planning to better address the needs of these families.

This study has helped to fill some of the gaps in the literature by describing previously undocumented patterns of MIH service use at the remote primary health service and hospital, across the continuum of care. It also provided new data on the transitions of care across remote and referral services and the impact of these transitions on quality of care, specifically in the postpartum period.

Understanding barriers faced by Aboriginal families to health care access is vital to reducing inequity and improving quality of care [55]. It is also essential that we have a good understanding of the barriers faced by clinicians when trying to provide MIH services for remote dwelling families. These issues had not been previously addressed but were investigated in this study, predominantly at the PHC level to help address this gap in knowledge.

The intention of this research was to provide pragmatic information that would be useful to the remote communities themselves, the health providers, and the policy makers and government who guide and plan the health services used by these remote dwelling families in the NT.

Since 2008, the findings of this study have been reported at regular intervals as they were generated to key stakeholders from the NT DoH, the *1+1* Advisory Group and local reference groups in the communities that comprise health board and council members, Aboriginal Elders, community members and HC staff.

Several changes and improvements have occurred to the organisation and structure of MIH services. Some of these changes emerged following our feedback to the stakeholders whilst others occurred independently. A number of health system changes have occurred that specifically affect the women and infants from the two study communities. These changes aimed to improve the continuity and quality of care across and within the health services and include:

- The development of an integrated maternity services model [84], incorporating the establishment of the Darwin Midwifery Group Practice.
- New leadership positions comprising of two Co-Directors of Integrated Maternity Services whose roles are ‘to lead and implement appropriate change at Royal Darwin Hospital and across Northern Territory hospitals in the provision of maternity services and secondly to lead the establishment of integrated maternity services across the Northern Territory’ [84, p9]. Also a midwifery-led position was designed to work in partnership with the Director of Obstetrics and Maternity Services.
- A program leadership position in child and youth health in the DoH.
- Designated midwife and child health roles in some remote communities including the two in this study. These positions are full-time, providing clinicians with more opportunity and resources for home-based or community-based delivery of care.
- Increasing the number of community-based workers and family support workers in remote communities.
- Changes to the Electronic Discharge System, which aim to streamline discharge processes.
- Implementation of a midwifery-led model of care in Antenatal Clinic at the regional hospital.
- Roll out of the ‘Healthy Under 5 Kids’ program.

A post-intervention evaluation as part of the *1+1* study is currently being undertaken. The evaluation will measure the impact that changes to service delivery have made on quality of care, service utilisation and MIH outcomes compared with the findings presented in this study.

## **6.5 Limitations**

A number of limitations need to be considered when interpreting the results of this research.

Firstly, mothers and infant subjects from the retrospective cohort study were selected from only two large remote purposively sampled communities of northern Australia and may not be representative of Aboriginal populations from other smaller remote communities, urban or regional areas.

Every effort was made to obtain complete medical record data. However, the quality of this data collection using paper-based medical records was compromised at times by incomplete documentation, conflicting information across different data sources, missing birth summaries and difficulty interpreting information in the records, thus affecting the validity and reliability of the results. These issues are often reported in data linkage studies particularly those based on existing medical records [85]. Data linkage between primary HC and hospital records was complicated by infants with multiple first and surnames and addresses; some misidentification of infants may have occurred.

The reliance on medical records at the HCs and hospital to retrieve retrospective clinical data may have resulted in an underestimate of service delivery if the service was used or clinical care was in fact provided but not documented by the clinician in the medical record. However, failure to document reflects poor quality of care as it prevents continuity of care, coordination of services and may result in duplication of services, which also impacts upon health costs, and undoubtedly inconvenience for the client. This may also bear on their perception of service delivery and influence their future use of the services.

In Papers 2, 3 and 5 a snowball sampling process was used to recruit participants. Although it was very useful for identifying difficult to reach staff, particularly in remote settings, it is important to acknowledge that this procedure may have introduced a sampling bias.

In Paper 3, the participant observation method reported is subject to observer bias. To improve the validity of the data and to check for inter-rater reliability, it is recommended that two or more observers undertake the observations independently [86]. This was not possible in this study for financial and logistical reasons.

In order to improve the validity of the data, HC and hospital clinicians independently verified the observations that were used in part to inform the patient journeys and



description of the health services during feedback sessions and at the *1+1* Advisory Group meetings. Multiple sources of data collection were also used in this study as a means of corroborating the data gained through the observations and, thus, improving the accuracy and reliability of the data.

Given the breadth of services used by mothers and infants in this study and the time intensive data collection process, the examination of quality of service delivery was limited to ANC in Paper 2, the discharge process in Paper 3 and routine growth and anaemia monitoring in the remote health service in Paper 5. During preliminary scoping discussions for this study, hospital and HC clinicians identified these specific areas of service delivery as in need of improvement but there was a lack of evidence to support this claim. Hence this was the rationale for the inclusion of these specific areas of service delivery in this study.

Given the mobility of these Indigenous populations across the NT, it is possible that women presented for ANC or PNC at other health services or were admitted to a hospital other than the regional hospital reviewed in this study. In this case our results of service utilisation and care provision in papers 1, 2 and 3 may be an underestimation. Similarly, infants may have presented for care at other health services or have been admitted to a hospital other than the regional hospital reviewed in this study in which case our results in papers 4 and 5 would also only underestimate service utilisation.

The introduction of linked electronic medical records systems in many NT health services that allow for sharing of patient records and information across different health sites will hopefully improve clinicians' ability to obtain complete information on every patient and reduce the duplication in tests and documentation, thus saving valuable time that can be spent on patient care.

## **6.6 Recommendations**

Action is needed in a number of areas to continue to improve the quality and effective use of MIH services at the primary and referral level. These are outlined below.

### **6.6.1 Service organisation and delivery**

- Ensure all remote dwelling women have access to care from a primary midwife when they relocated for birth
- The development of a 'communication protocol', similar to that developed for Victorian public maternity services and the Maternal Child Health Service [31]. This protocol would promote standardised processes for the transition of care across MIH services and serve to foster mutual understanding of the different roles within the health services at the hospital and RHCs.
- Move MIH health care in RHCs from an acute, fragmented medical model based at the HC to a more inclusive, participatory, family-friendly model based on continuity of care and carer. This could be achieved through the establishment of multidisciplinary MIH teams within the HC and include the designated midwife, CHN, DMO, AHW and community-based workers who provide care and bicultural education in a community setting
- Midwifery Group Practice midwives or paediatric nurses (for infants admitted to hospital following birth) to be involved in the coordination and compilation of the discharge paperwork, together with medical staff. The person completing the summary should be known to the mother/infant or designated to her community and provide a phone handover following any hospital admission and before hospital discharge, where possible.
- Establish regular communication and case management meetings between DMOs and midwives at the HC and a mechanism for communication between HC staff and hospital staff for case management.
- Better integration of Aboriginal health belief systems into service delivery.

### **6.6.2 Workforce**

- Review and determine staffing numbers for MIH services in RHCs by considering local patterns of health service use, birth numbers using local birth records and specific community health needs and resources.
- All women and infants should have 24 hour access to an appropriately skilled and qualified maternity and child health care provider within the remote community at all times.

### **6.6.3 Clinical governance and leadership**

- Establish senior leadership roles in child health nursing services, similar to those previously described for maternity services.
- Pilot and evaluate a discharge coordinator position for mothers and infants.
- Regular monitoring of clinical practice by management and implementation of designated facility-based Quality Improvement (QI) teams. QI teams could undertake regular auditing of service delivery and clinical findings within their health facility and measure outcomes using indicators specific to the needs of remote dwelling Aboriginal mothers and infants in the NT [87-88].
- Regular feedback of QI audit findings to HC and hospital staff and the NT government level and subsequent implementation of action plans as part of a quality improvement cycle.
- More support for HC and hospital staff including guidelines that articulate exactly how HC midwives, nurses, DMOs, AHWs, community-based workers and specialty outreach staff work together.

### **6.6.4 Education and training**

- Cultural security training should be part of mandatory education undertaken by all non-Aboriginal clinicians prior to commencing employment at the hospital or in remote Aboriginal communities. This education should include Aboriginal health belief systems and child rearing practices. Education should also be reviewed annually.
- All staff providing MIH care should be trained in providing targeted, culturally appropriate information and interventions or referral where appropriate for smoking cessation, alcohol use, foetal anomalies, domestic violence and mental health issues.
- Remote HC staff should be provided with sufficient orientation and training in the use of the local guidelines, primary care manuals (WBM and CARPA), referral practices and documentation prior to commencing employment in the community.
- Training programs must be reviewed to ensure they prepare students fit for practice.

- Remote HC nurses working with children should be appropriately qualified to do so or be working towards obtaining a child health qualification.
- Prior to commencement of employment in remote health facilities, all clinicians should fulfill mandatory competencies in maternal and infant care. All RHC non-maternity trained staff should attend the Maternity Emergency Care Course [89] and receive regular up-skilling in maternity care and supportive supervision.
- Remote HC staff should have opportunities to undertake distance education modules to build skills and knowledge directly relevant to remote area practice, such as through the Post Graduate Diploma in Child Health at Charles Darwin University in the NT which is primarily designed for RANs working with Aboriginal children.
- All staff in HCs and the hospital should have access to designated 'specialist' mentors or preceptors who provide regular supportive supervision and opportunities for knowledge and skills refresher training in the workplace. Opportunities should also exist for MIH HC staff to undertake rotation periods in the hospital and *vice versa*.
- Aboriginal people to have a larger leadership role in health service management and service delivery. Ensure health boards are more engaged and in control of health service delivery in remote communities.
- Aboriginal Health Workers and community workers to have a greater role in health education and health promotion activities or interventions, such as for growth faltering. This should be provided at places other than just the HC and be tailored to the needs of the community members.

## 6.7 Future Research Directions

A large amount of linked, paired maternal-infant data was collected. Further analysis is planned to investigate associations between health service use by mothers and clinical outcomes among infants using conditional logistic regression. For example, do women who present for fewer AN visits have children who are sicker in the first year? Is there an association between maternal anaemia and subsequent infant anaemia? These questions have not been investigated in remote dwelling Australian Aboriginal populations and the data collected here were powered with these questions able to be addressed.

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