



Aboriginal families STUDY

Final Report on the Community Consultation

April 2009



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For more information about the project please visit
<http://www.mcri.edu.au/AboriginalFamiliesStudy>

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Abbreviations

AHCSA	Aboriginal Health Council of South Australia
CHSA	Country Health South Australia
COAG	Council of Australian Governments
CYWHS	Children Youth and Women's Health Service
FaHCSIA	Department of Families, Housing, Community Services and Indigenous Affairs
HealthSA	Department of Health South Australia
MCRI	Murdoch Childrens Research Institute
NHMRC	National Health and Medical Research Council
SAAHP	South Australian Aboriginal Health Partnership
SGRHS	Spencer Gulf Rural Health School
VACCHO	Victorian Aboriginal Community Controlled Health Organisation
UniSA	University of South Australia

Foreword

This report is the outcome of more than 12 months of consultation with Aboriginal community organisations, communities, women's groups, service providers and policy makers in South Australia. Consultations were held in Adelaide, Port Augusta, Port Lincoln, Whyalla, West Coast, mid North and York Peninsula, Ceduna, Coober Pedy, Yalata, Point Pearce and Mt Gambier.

Telling the story of how we came to undertake the consultation requires looking back to 2006 when Jane Yelland, Georgie Stamp and I first had discussions with staff at the Aboriginal Health Council of South Australia (AHCSA) about the possibility of collaborating in research about maternity and postnatal care for Aboriginal women and families living in South Australia. Together with Jeffrey Robinson and other researchers, we were planning another larger research project to survey over 8000 Victorian and South Australian women giving birth over a two month period in late 2007. We knew that the survey would not include many Aboriginal* mothers, and wanted to discuss ways that Aboriginal women and families might be included in the research. At our initial meeting with staff at the AHCSA, we proposed the idea of seeking funding to facilitate consultations with Aboriginal community organisations and communities in South Australia as a way to seek input into development of the research.

In May 2006, Jane, Georgie and I were invited to attend an AHCSA Board Meeting in Whyalla to answer questions from Board Members about our proposal. We were asked why we wanted to do the project, who would own the information gathered in the course of the research, and what would come out of it for Aboriginal families and communities. Most of all Board Members wanted to know "Will it make a difference?"

Answering these questions and listening to what Board Members had to say about past experiences of poorly conducted research heightened our awareness of the potential risks to Aboriginal communities of research undertaken by non-Aboriginal researchers, and the importance of establishing strong partnerships with Aboriginal communities. It also made us acutely aware of the frustration caused by research reports that describe well-known issues and problems, without leading to any improvement in conditions, opportunities or services for Aboriginal families.

After this meeting, the AHCSA Board gave us 'in principle' support to proceed with an application to the National Health and Medical Research Council (NHMRC) for funding to undertake a 12 month consultation in South Australia. This application was successful and we were awarded a grant commencing in 2007. The South Australian Department of Health also contributed funding for the consultation.

* The term 'Aboriginal' used throughout this document is intended to refer to people of Aboriginal and/or Torres Strait Islander origin.

Two part-time project officers – Roxanne Miller and Angela Sloan – were appointed in June/July 2007. Hayley Wilson joined the team, replacing Angela Sloan, from February 2008. An Aboriginal Advisory Group - with representation from metropolitan and regional health services, the AHCSA, Aboriginal Elders and Aboriginal Health Workers with expertise in maternity and postnatal care - was established in September 2007. We are grateful to Jackie Ah-Kit, Brian Butler, Alwin Chong, Harriette Coleman, Glenise Coulthard, Karen Glover, Margaret Hampton and Rebecca Kimlin for their guidance and mentoring of the research team, their advocacy on behalf of the project, and for their support of the project officers undertaking consultations.

In this report, we describe the consultation process and the views of people who took part. The purpose of the consultations was twofold. First, we wanted to find out whether there was community support for research about Aboriginal women's experiences of maternity and postnatal care. Second, we wanted to seek input into the research questions, methods and ways of conducting the research, should it go ahead. The consultation process, although extensive, did not set out to seek the views of all Aboriginal community organisations, service providers or communities in South Australia. We did hope to build relationships with a broad range of organisations and people potentially interested in the research. While the views presented are not necessarily representative of everyone who may have an interest in the research, the project officers and members of the research team met with many people in a large number of locations in remote, rural, regional and urban areas of South Australia. The consultations highlighted many consistent concerns and provided many practical suggestions and ideas about how the research should be developed.

There was strong support for the research to proceed in South Australia, provided that things happen as a result, to make a difference to the lives of Aboriginal families. We are now moving forward with development of the research phase of the project with this goal at the forefront of our minds. We hope that this report provides an accurate summary of issues discussed during the consultations and welcome your feedback and further suggestions.

Stephanie Brown

Head of Research Group
Healthy Mothers Healthy Families Research Group
Murdoch Childrens Research Institute
February 2009

1. Background

This project arose in the context of planning for a state-wide postal survey of recent mothers called the *Healthy Mothers Healthy Families Survey* that was carried out in South Australia and Victoria in early 2008 (See: <http://www.mcri.edu.au/HMHFSurvey/>). The 2008 Survey builds on three previous Victorian surveys of recent mothers conducted in 1989, 1994 and 2000 (Brown S, 2003). The purpose of the surveys is to find out what women who have recently had a baby think about the care and support they received during their pregnancy, labour and birth and the first six months post birth, and to use this information to inform the planning and delivery of maternity and postnatal services.

The three previous Victorian surveys and the recent Victorian and South Australian Survey were conducted by Victorian researchers now based at the Murdoch Childrens Research Institute in Melbourne. The researchers planning the 2008 Survey recognised that a postal survey was not a good way to encourage Aboriginal women to participate in the research. In February 2006, they approached the Aboriginal Health Council of South Australia (AHCSA) and the Victorian Aboriginal Community Controlled Health Organisation (VACCHO) about working in partnership on a project to provide avenues for Aboriginal women's voices to be included in the research.

The *Aboriginal Families Study* is the name given to the South Australian project that has grown out of these discussions. It was agreed that the first stage of the project would involve a 12 month period of consultation with Aboriginal community organisations and communities in regional, rural, remote and urban areas of South Australia. Two Aboriginal Project Officers were appointed to assist with the consultation, taking up appointments based at the Spencer Gulf Rural Health School in Port Lincoln, and the University of South Australia in Adelaide in June/July 2007. This report summarises findings from the consultations undertaken between October 2007 and December 2008.

The consultation phase of the project involved collaboration between:

- the Aboriginal Health Council of South Australia (AHCSA)
- the Healthy Mothers Healthy Families Research Group, Murdoch Childrens Research Institute (MCRI)
- the University of South Australia (UniSA)
- Spencer Gulf Rural Health School (SGRHS), University of South Australia and University of Adelaide.

The Healthy Mothers Healthy Families (HMHF) Research Group at MCRI signed a project agreement with the AHCSA in September 2007. An Aboriginal Advisory Group was established in September 2007 and has met regularly every six weeks to provide advice and direction to the research team.

Funding for the consultation phase was provided by an NHMRC project grant and a grant from the Department of Health SA.

2. Structure of Report

This report provides an overview of phase one of the Aboriginal Families Study in South Australia – the consultation phase.

Section one covers background to the study.

Section three outlines the goals of the consultation process determined in collaboration with the Aboriginal Advisory Group, and also documents the first steps in the consultation process.

Section four reports on how consultations were conducted in the Northern and Western regions of South Australia, and in the Adelaide metropolitan area and southern region. This section also includes reflections on strengths and limitations of the consultation process.

Section five provides a detailed account of the major findings of the consultations in each region, including key recommendations for development of the research.

Section six outlines the next steps in developing the research phase (phase 2) of the project.

3. First steps

Our first steps involved the appointment of two Aboriginal Project Officers – one based in Port Lincoln and the other in Adelaide – and the development of a Project Agreement between the AHCSA and the Healthy Mothers Healthy Families Research Group at MCRI.

The Project Officers – Roxanne Miller and Angela Sloan – were appointed in June/July 2007. A joint workshop bringing together the Victorian and South Australian research teams was held in Melbourne in July. At the workshop, we started to discuss ways of working to promote the project and seek input from Aboriginal communities in each state. A set of questions were developed as a guide for Aboriginal community members and Aboriginal organisations as to the issues we were interested in consulting them about. Hayley Wilson was appointed as Project Officer in early 2008, replacing Angela Sloan.

A South Australian Aboriginal Advisory Group was established and met for the first time in September 2007. Terms of reference and composition of the Advisory Group were determined in consultation with the AHCSA and members invited to attend the first meeting of the Advisory Group in September 2007. The agreed terms of reference and membership of the Advisory Group are contained in Appendix 1.

The research team worked in partnership with the Aboriginal Advisory Group to develop the consultation process. Advisory Group members provided advice regarding the best ways to consult Aboriginal communities in regional, rural, remote and urban areas. The goals of the consultation process were discussed by the Advisory Group at meetings held in September and October 2007. The set of questions developed by the research team at the joint workshop held in Melbourne were also discussed by the Advisory Group and approval was given for these questions to be used by the Project Officers as a guide for the consultations (see Appendix 2).

The goals for the consultations approved by the Advisory Group were:

- To inform community organisations and community members about the project
- To engage community organisations and community members in the process of designing and conducting the study by building and strengthening relationships and partnerships
- To seek community input into the design, methods and content of the study
- To provide feedback to community organisations and community members and check that we have interpreted community input correctly

- To provide information to community organisations and community members on development of phase 2 of the project.

The goals of the consultation recognised the importance of building relationships between community members and the project. Through the consultations we hoped to hear what Aboriginal women, Elders, workers in Aboriginal community organisations, members of women's councils and other community members had to say about whether a project about Aboriginal women's experiences of pregnancy, birthing and postnatal care would be valuable. Importantly, if the research was to proceed, we wanted to know how community members thought it should be conducted.

Formal consultations commenced in November 2007. A flyer and 'frequently asked questions' sheet were developed and used to promote the project at community events and via community networks (see Appendix 3 and 4). There were many similarities in the approaches of Roxanne and Hayley to the consultations, but there were also differences. Because of the nature of the communities being consulted in different regions of the state, the location of policy staff in the Adelaide metropolitan region, and the links between the Project Officers and the communities in which they consulted, a variety of approaches were used to make sure that the consultation process was as inclusive and as informative as we could make it. The different approaches used are discussed in the next section.

4. Consultation in Northern and Western regional areas

Approach to the consultation

The researcher appointed to facilitate the consultation in the northern and western communities was Roxanne Miller. Roxanne has strong family connections with Mirning, Wirangu and Kokatha language groups of the west coast and friendship connections with other cultural groups of South Australia placing her in an ideal position to visit and consult widely.

The consultation used ways of working that Aboriginal women from rural and remote areas are familiar with both culturally and traditionally. Roxanne has been taught those ways from her grandmother and aunties who are also her mothers. These ways involve respect and seeking the correct connections with senior community women before approaching other women.

Aboriginal women live in cities, rural towns, homelands and traditional lands. Many women travel between areas because of past and present family connections. Introductions happen through kinship and trusting partnerships follow if the correct processes and protocols are used (Franks et al 1996).

In this consultation the following steps were taken:

- The first approach was made by contacting the appropriate senior or elder community member to organise a visit. This was usually through the Aboriginal Health centre or clinic. The go-ahead was given for the visit after the community had been consulted, usually by the community council or board members.
- Timing was important because of cultural obligations and responsibilities, community activities, funerals and weather conditions (e.g. summer temperatures and winter road conditions).
- Because the distances between rural and remote communities in South Australia can be vast, overnight stays were required. Motels were used if available in the community, or alternatively overnight stays were arranged with relatives or community members.
- The consultation process is very time-consuming for communities and provision of refreshments was essential. The team acknowledges that the sharing of food has a

significant role in the relationship structures within the kinship network and Aboriginal community life.

In a recent publication Champion et al (2008) describe a research method of reaching participants that fits in with and utilises the kinship structure in Aboriginal life they called 'pass-me-around'. Using this approach, the researcher was 'passed around' after contacting people known to her who then suggested further contacts and ideas to reach women and community groups.

After the first contact, documentation explaining the aims of the research and consultation process was sent to key community members, councils and boards. Then dates and meeting times were arranged. Many times these were changed because of community responsibilities and obligations.

The meetings all followed a similar format. After introductions, Roxanne Miller explained her role in the research process and participants were invited to discuss and answer a series of questions. A modified questionnaire that had been used in another study with Aboriginal women in Victoria (Campbell S & Brown S, 2004) was circulated and discussed. Women gave feedback about all aspects of the questionnaire.

Formal consultations and informal information sharing happened in towns and communities that included homelands, remote communities, community controlled health services, women's groups and regional town residents. Sixteen communities and groups involving a total of 121 women were consulted formally using the pre-specified questions for consultation (Table 1). Informal information sharing was also conducted in 5 locations involving a further 98 women (Table 2).

Table 1. Communities or groups consulted in Northern and Western regional areas

Communities or groups consulted (16)	Number of participants	%
Port Lincoln community women	23	19.0
Ceduna/Koonibba Health	4	3.3
Ceduna women's group	4	3.3
Cooper Pedy	10	8.3
Bullinda homeland	4	3.3
Koonibba women	9	7.4
Dinaline homeland	4	3.3
Yarralina homeland	4	3.3
Scotdesco homeland	8	6.6
Goongawa Dundee	7	5.8
Yalata	9	7.4
Copley	10	8.3
Nepabunna	2	1.7
Port Augusta Pika Wiya	7	5.8
Port Augusta AMIC workers	7	5.8
Port Augusta	9	7.4
Total	121	100

Table 2. Informal information sharing Northern and Western regional areas

Informal information sharing (5)	Number of participants	%
Port Lincoln Aboriginal Health Service	30	30.6
Port Lincoln women's gatherings	38	38.7
Mallee Park women's gathering	15	15.3
Maree women	8	8.2
Whyalla Nuyarra Well-being Centre	7	7.2
Total	98	100

Roxanne Miller, who is based in Port Lincoln, travelled distances of up to 800kms to conduct the consultations in rural and remote locations. Roxanne has extensive cultural knowledge of the west coast. Importantly, this involves a commitment to following the protocols of host communities, keeping in regular contact and immediately incorporating any changes in plans that can arise from community responsibilities and obligations.

The funding for the Aboriginal Families Study allowed 12 months for the consultation. Two visits would have allowed more time to establish relationships and develop the research partnerships. However, instead of a second visit, a summary of the consultation findings was mailed to each community.

Roxanne Miller attended the inaugural ACHSA research capacity building course in 2008 and was awarded a PHC_RED scholarship to write up the findings of the consultation.

Roxanne continues as a member of the research team where, in partnership with the Aboriginal Advisory Group, she has a key role in developing the questionnaire and contributing to the study research protocol. Roxanne is committed to continuing to consult with the communities and research partners as the study progresses, returning and consulting on research findings and developing any recommendations for changes in practice or further research that arise from the study.

5. Consultations in Adelaide metropolitan area and Southern region

Approach to consultations

Angela Sloan was appointed as the project officer for the metropolitan and southern region in July 2007. The first publicity for the project happened at the Kura Yerlo Open Day and the South Australian Aboriginal Women's Gathering in November 2007.

Hayley Wilson joined the research team in early 2008. She and Fiona Arney began the formal consultation process in early 2008, with Hayley taking sole responsibility for consultations from May 2008 onwards. A snowball sampling strategy was used and key people to be consulted were identified through existing professional and personal networks of the research team members and the Aboriginal Advisory Group. The AHCSA played a central role in this, with many interviews flowing from a meeting to disseminate a report from a previous research project.

A range of publicity events were attended by Hayley Wilson and Fiona Arney (see Appendix 5). These included the Prime Minister's Apology event in February at Elder Park, and Turkindi meetings at which the study was represented at regular meetings from March 2008. Hayley Wilson attended the Taoundi College Health Open Day in May 2008 and spoke with community members and Taoundi College staff about the study. Alwin Chong spoke at the HDA Research Day about the study in May 2008. Fiona Arney attended the Reconciliation event in June 2008 and provided information about the study on the Turkindi stand. Hayley Wilson and Karen Glover attended an Indigenous Cultural Consultants meeting and spoke about the study in August 2008. Hayley Wilson and Fiona Arney also took the opportunity of a visit to the APY Lands in September 2008 to speak with staff at Nganampa Health Council and in Amata about the study.

A range of people, organisations and community groups were consulted (see Table 3). This included community health services, mums' and women's groups, Elders' groups, playgroups, parenting education and art groups. All the major divisions in the Department of Health (including CYWHS, CNAHS, SAHS) covering all major birthing hospitals, maternity services and early postnatal services in Adelaide were consulted. We also spoke to staff at the AHCSA and Nunkuwarrin Yunti (representing Aboriginal community-controlled health services). A total of 104 people were consulted in the Adelaide metropolitan area and southern region.

Table 3. Organisations and groups consulted in the Adelaide metropolitan region

Organisation/Group	Number of people consulted
Aboriginal Health Council of SA	1
Women's and Children's Hospital	3
Nunkuwarnin Yunti	1
SA Health	2
Karpandi - Westcare Elders Art Group	6
Primary Health Care Services, Aboriginal Health Team – East	5
Neporendi	6
Aboriginal Family Support Services	6
Northern Women's Community Health Centre	2
Muna Paiendi	1
SA Health – Protection Health & Wellbeing Coordination Committee	18
Kura Yerlo Elders Group	9
Christie Downs Primary School – Nunga Playgroup	10
Playford Community Health Centre-Arts Group	11
Children, Youth and Women's Health Service – Parenting Network	10
Central Northern Area Health Service	2
Noarlunga Health Service	2
Primary Health Care Services, Aboriginal Health Team East	5
Breastfeeding reference group	1
Children, Youth and Women's Health Service	1
Gawler Health Service	1
Pt Adelaide Primary Health Care Centre	1
Total	104

Some reflections on the consultation process from Hayley Wilson

“Initial consultations with two Aboriginal women's groups using a PowerPoint presentation about the study and the provided standard set of questions resulted in minimal interaction. It became clear that this formal approach would not suit many women. In most groups some women commented that 'Aboriginal people are the most surveyed people in the world and still nothing ever gets done'. I realised that a different approach would be necessary if I really wanted to get the women to open up to me and not feel that they were merely survey objects. I recognised that I needed to modify my approach and after some careful reflection decided to focus on some areas that I had in common with the women I was consulting.

At the next women's group I attended I introduced myself as an Aboriginal woman and mother of two year old twins. I felt an immediate difference to the way the women responded to me. I then asked if we could have a talk or yarn about either their own pregnancy experiences (both good and bad) or those of friends and relatives. I then casually asked some questions that related specifically to the study as part of the discussion. This approach was much more appropriate and more productive because I found that I could join in and that the women opened up to me more as I understood what it was like to be pregnant and to receive care from maternal health services.

Being challenged about the over-surveying and lack of change forced me to consider my attitude towards the Aboriginal Families Study. I decided that I needed to clearly state my position to every group. That is I could only be involved in a study where the outcome was focussed on the introduction of real change and not merely gathering data.

When consulting with service delivery providers I found the standard set of questions were appropriate in guiding the consultation. At these consultations I saw that participants were willing and quite happy to provide feedback. This group was clear that the responses they provided would potentially improve service delivery to the Aboriginal community as well as help them in their roles as service providers. Many consultations as previously indicated focussed on the study in a broad sense rather than specifically on provided questions. In terms of the study's initial framework the fact that all groups did not discuss every question could be seen as a limiting factor. However, as suggested more fruitful dialogue emerged in many groups when the questioning approach was modified.

A further limitation involved the age range of the participants. Young women – those from between 15 and 25 – were under-represented. Some women suggested that

High School students should be incorporated into the study, recognising that there will be ethical implications regarding informed consent for this population.

A major issue not covered in consultations involved the role of fathers. One respondent pointed out that including fathers could provide a better understanding of social issues within the family. If, for example, domestic violence could be discussed, this would be of great value to mothers and their babies."

6. Major findings of the consultation process

6.1 Findings from the Western and Northern region consultations

The set of questions approved by the Advisory Group were used as a guide for the consultations. Responses are collated below.

1. Is a study about pregnancy, birthing and postnatal care for Aboriginal families needed?

All participants agreed that the study was needed but there was much discussion and frustration about the amount of research that had already been done on Aboriginal people that did not provide any benefits or feedback to communities. There were two main themes identified that relate to this question: the importance of Aboriginal researchers and communities guiding the research, the issue of remoteness and implications for quality and access to services.

2. What issues/topics should be included in the study?

The issue most raised was the need to find out the availability of educational material, support and information for Aboriginal mothers during pregnancy, labour and after the birth. Another theme was related to questions about social and emotional well-being issues. Some groups included questions about fathers' involvement, being included in decision-making, and home visits by health workers.

3. What information would be most valuable for us to collect?

This question led to lots of discussion. Common themes were:

- Whether women had a support person with them, or were asked if they would like a support person with them, at all stages of their pregnancy and birthing experience
- Was the baby's father involved in pregnancy, labour and birth and after the birth?
- Were any Aboriginal health workers or medical staff involved in the care?
- Family history and issues of grief and loss
- What support was available for new mothers in the early days at home?

- Did the mother have to leave her community for care for herself and/or her baby? If so was accommodation adequate? What were the transport issues? What were the out of pocket expenses?
- Did women get a choice of doctor (e.g. male/female)?

4. What would help Aboriginal communities and community organisations in advocating for better services for Aboriginal women and families?

Several suggestions were made:

- Promoting awareness by recognizing strong voices and leadership of Aboriginal women in their communities
- Speaking out for sustainable funding for programs on women issues
- More training for Aboriginal health workers
- Having more Aboriginal mentors
- Liaising with mothers and grandmothers groups in traditional and non-traditional settings
- Involving senior Aboriginal women with knowledge of traditional care in their community.

5. What are the best ways to inform Aboriginal women and families about the study? (e.g. via Aboriginal health services, via community and family (kinship) networks, via Aboriginal hospital liaison officers/Indigenous cultural consultants, via community newsletters, other methods).

The consultation reinforced that Aboriginal service providers are an important source of contact with community women. Several other suggestions were also made:

- The first approach is to initiate community consultations with Elders who make contact with community aunts, grandmothers and new mothers.
- If a women's gathering or camp is planned the researcher would seek an invitation to attend.

- Otherwise, organise a barbecue or lunch at a suitable time for the community and encourage as many women as possible to participate.
- Other ways of letting Aboriginal women know are by the Nunga grapevine/word of mouth, Umeewarra Media, Aboriginal TV programs, and advertising in local papers and local commercial TV spots.

6. How do we engage young women (under 18) to take part?

There is considerable concern about young mothers. Women in the groups and consultations were fully engaged in this question. It was agreed that building the trust of the young women was vital. Suggestions were to involve the grandmothers, mothers, aunties, sisters and senior community women. Some women may want to have company, either a senior community woman, friend and/or relative with them during the interview, others may not. Other ideas were to access the services where young women go and to engage young women's leaders through their friendship networks.

7. What are the best ways to collect information in the study?

Almost without exception the communities and groups consulted wanted face-to-face interviews with a trusted Aboriginal woman. They also wanted an interpreter to be available when English was not the first language of the woman.

8. How should participants be reimbursed for their time?

Many suggestions were made about ways to reimburse women for their time. These included:

- a gift or gift vouchers for the family, baby or mother
- personal items for the mother such as deodorant, a nightie and slippers or a pamper pack
- a lunch outing
- items for baby
- a taxi voucher
- supermarket vouchers
- baby and family photos

- certificate of acknowledgement
- a summary of the findings.

9. How should information gathered in the study be reported back to participants, to community organisations and to community members?

Before the study is completed it was suggested that a newsletter be sent on a regular basis giving updates of the progress of the study. Every community or group consulted wanted to have a visit from the researcher to report back the findings from the study. Most would like to be invited to a women's community gathering with a barbecue or luncheon. Several specified they would like a Power Point presentation and a summary of the findings in booklet or handout form as well as the full report. It was also suggested that Certificates of Appreciation were presented to each community. If key women were unable to attend a phone link-up or email could be acceptable.

10. What needs to happen/what do the researchers need to do to ensure that there is community control and ownership of information?

In every group and community, the strong view was expressed that they wanted acknowledgement for their involvement in the consultation process.

Participants in the consultation wanted to be acknowledged at the beginning of the report. Other suggestions were for certificates of participation, a barbecue or luncheon, and for copies to be made available of the full report and findings, as well as plain language summaries.

6.2 Findings from the metropolitan area and southern region

As noted in Section 5, the metropolitan and southern region consultations happened over a shorter time frame. Consultations were held with community and women's groups and with service providers and policy makers. Although publicity about the project was commenced in November 2007, consultations did not commence until February 2008. Although the set of questions for the consultation approved by the Advisory Group were used, discussions were often informal, especially with community and women's groups. The consultations identified many issues for the research team to consider. Key issues are summarised below.

Key findings

The consultation process showed that there is support for the study. However, the dominant message from both community members and Aboriginal and non-Aboriginal service providers was that the study results *'must be translated into action'*.

Feedback about the process for interviewing women emphasised the importance of the way that women are invited to tell their individual stories. Community members saw the telling of stories as an important part of the research. Women wanted to make sure that their stories were heard and understood, and not just be asked to answer questions. They wanted their stories to inform recommendations coming out of the research and saw this as an important first step in the introduction of real change. Recording women's stories was also seen as providing a crucial cultural link between this important Aboriginal tradition of storytelling and the more distant, and potentially fragmented, westernised process of information gathering using structured interviews and questionnaires.

Significantly, senior Aboriginal staff in the South Australian Department of Health were very supportive of the study, recognising that it will be done in ways that are culturally appropriate for the women and useful for services. They suggested embedding researchers in health service settings would assist in the communication of study results to participating community members as well as in recruiting women to the study.

What areas and issues should be covered by the research?

The consultation process identified the following areas that the study should cover. These areas were consistently raised by community members and Aboriginal and non-Aboriginal service providers.

Transport & Accommodation

Difficulties with and access to transport are consistently experienced by Aboriginal women as a barrier to attending health service appointments. Few women have the support mechanisms in place or the means to have their children minded while they attend antenatal appointments and often find it too difficult to use public transport. Aboriginal women generally access antenatal services later in pregnancy and with less frequency. In South Australia in 2007, 27% of Aboriginal and Torres Strait Islander mothers attended their first visit for antenatal care at less than 14 weeks gestation compared with 12% of non-Aboriginal mothers; and 55% of Aboriginal and Torres Strait Islander mothers attended seven or more antenatal check-ups, compared with over 88% of Caucasian mothers (Chan A, 2008). Late attendance for antenatal care has been shown to be a risk factor for poor birth outcomes among urban Aboriginal women (Panaretto K, 2006).

The pregnancy and child birth care options available to women differ according to where they live. Service providers were aware that maternal and infant health outcomes are poorest for women living in remote and very remote parts of South Australia. This area was of particular concern to Aboriginal service providers. Aboriginal infants are more likely to be born pre-term, more likely to be of low birth weight and therefore more likely to require an extended stay in the Neonatal Intensive Care Unit (NICU) in hospital. For the family this may require a long period of being away from community. This is particularly difficult if there are other children needing care. The consultation identified that the travel and accommodation needs of Aboriginal women are particularly important and that they are not adequately addressed.

Both Aboriginal community members and Aboriginal and non-Aboriginal service providers stressed that until all Aboriginal mothers have better access to support services, including transport and accommodation, Aboriginal women will continue to have poorer health outcomes than non-Aboriginal women.

Continuity of Care

Another issue of concern for women is that they often see many different health professionals throughout their pregnancy. This issue was highlighted by both Aboriginal and non-Aboriginal service providers as being of particular concern for young Aboriginal women and for traditional women travelling from remote communities. Given that many Aboriginal women face language and cultural barriers, seeing different non-Aboriginal health professionals when pregnant represents a further hurdle.

Service providers said that women often do not come back for their next appointment if they feel that they have not been treated respectfully, in the same way as other women, or when they find it too stressful dealing with a number of different health professionals. This is despite

studies which have consistently demonstrated that continuity of care/r improves satisfaction for both women and health professionals, boosts health outcomes and reduces intervention rates (Hodnett E, 2008). Most women said that they would be more inclined to attend appointments regularly if they knew that they would be seeing the same health professional at each visit. Both Aboriginal community members and service providers said that having the same carer throughout a women's pregnancy can enable the building of a trusting relationship which could be of importance in ongoing support after the pregnancy.

Aboriginal Health Professionals

The need for more Aboriginal health workers, nurses and midwives throughout the South Australian health care system was strongly voiced by both Aboriginal and non-Aboriginal community members and service delivery providers. Such increases are seen as a means by which women will have more choice and more opportunities for continuity of care.

Many women maintained that the provision of antenatal care in large hospitals is often inappropriate and unwelcoming. Responses highlighted that some health professionals did not understand Aboriginal culture and the ways Aboriginal people might interact. Many lacked the ability to talk to Aboriginal women. This issue raised the necessity of having non-Aboriginal service providers trained in Aboriginal culture and ways. Implementing such training would facilitate sustained access of Aboriginal women to the maternal health care system.

Postnatal Services

Many women taking part in the consultation said that there were major gaps in postnatal services. Providing access to information and support for parenting and infant feeding is a crucial service that women wanted to know about. Social support services and providing information about how to access services for women who are under stress, dealing with depression, or grieving the loss of a baby was seen by many women as an area that was lacking.

Both Aboriginal and non-Aboriginal community members and service providers stressed that the needs of women do not end when they leave hospital. Women under stress, dealing with depression, a multiple birth or the loss of a baby, require support plus information about how to access the services they need. The consultation process identified this as an important area that needs to be addressed. Similarly, housing, domestic violence and drug and alcohol problems were identified as areas where women would like support and was also revealed as a gap during the consultation process.

Many women feel that once they go home from hospital they are isolated from mainstream health and social services. The consultation highlighted that many women do not know what services are available such as children's services, women's groups, health and education and want to have information about these areas. Knowing the choices available to them through the use of appropriate resources and trained personnel was seen as helping to build trust and greater understanding of local community health services for women and families with a new baby.

How should the research be conducted?

Both Aboriginal and non-Aboriginal community members and service providers contributed valuable ideas about the further development of the study.

Recruitment of participants

Community members suggested utilising a wide range of approaches in order to invite women to participate. These included:

- Re-visiting those groups and individuals involved in phase 1 (2008) was one approach favoured by many community members. This could encourage further participation by these women and also enable them to suggest others, perhaps new mothers, to become involved. Using such previously established networks as a basis for further recruitment reinforces to community members the importance of the study and its development. Also many women wanted further involvement because they believed the study was worthwhile. Another advantage of accessing established networks would be that individuals within such groups already know of additional associations such as sporting groups, playgroups, kindergarten and high schools. These could all be sources of contacting young mothers.
- Community members emphasised that hospitals would be a crucial point of contact for new mothers. The best time for health workers to sit down with postnatal women in hospital is at times without visitors. Aboriginal health workers could also visit families at home where hospital meetings did not eventuate. Individual time and support for new mothers would be of great value generally as well as assisting recruitment.
- In communities where Elders are likely to have knowledge of and relationships with new mothers, accessing their 'inside information' could be helpful to the study. Aboriginal community members strongly recommended this as a means of recruitment.

Aboriginal and non-Aboriginal service providers made a number of other suggestions and comments about recruitment of women to the research:

- In particular, they recommended using organisations such as the Children, Youth and Women's Health Service (CYWHS) and Indigenous Cultural Consultants (ICCs) as a means of promoting the study and attracting participants
- Service providers were in agreement about the value of the study and its increased potential if diverse groups could be combined in settings which maximised their contributions. Inviting women (perhaps those identified by the 2008 networks) to well known Aboriginal organisations or venues such as Nunkuwarrin Yunti for a day was another strategy. Providing transport, lunch, childcare, health checks for different age groups and some reimbursement could assist in making the study very attractive.
- Service providers were also clear that it was vital to value and recognise that Aboriginal women have their own lives and issues. Accessing the study needs to be appropriate for individuals. There should be no pressure for women to participate and their decision about whether or not to participate needs to be respected by researchers.

There was broad support for wide distribution of a range of information/promotion material about the study, and how to participate, via Aboriginal Health Services, GP surgeries, Playgroups, Parenting networks , hospitals, community newsletters, Koori mail and Indigenous radio and TV.

Provision of information to participants: about the study and confidentiality

All groups involved in the consultation process were clear that all Aboriginal women participating in the study need to know the importance of their individual role in the study. Telling their stories and contributing their experiences would add important dimensions to the collection of information and greater understanding of ways that changes could be introduced; changes which could lead to significant gains in Aboriginal maternal health services that would benefit the Aboriginal community. In addition, service providers recognised the importance of reassuring participants that the system can and will change. Part of this reassurance would involve ensuring that interested participants would see reports and hear details of the study's progress.

Participants' confidentiality was a major concern from service providers. Interviewers need to give reassurance to interviewees that neither their involvement nor their responses to questions would be provided to hospitals, doctors, Centrelink or FaHCSIA. In addition, participants need to know that they can choose whether or not to answer individual questions and that they are able to stop the interview if they become uncomfortable or wish to withdraw for any reason.

Methods for reimbursing participants

Several suggestions were made by both Aboriginal and non-Aboriginal community members and service delivery providers. These included:

- financial reimbursement for their time
- a choice in gift vouchers such as supermarket, Westfield or movie
- a gift basket for mum and/or baby
- luncheons
- transport
- childcare

In addition to the above suggestions about tangible reimbursement, one respondent suggested that the interview process itself also represented an opportunity to further 'reimburse' participants. Providing information about the availability and range of services could be both valuable and be something to give back to participants.

The interview process: the nature of relationship between interviewer and interviewee and interviewer sensitivity

Service providers were emphatic about the need for interviewers to be multi-skilled. In addition to having training specific to the study, interviewers will need to be well informed about birthing processes, care of women during childbirth and technical language such as episiotomy. The ability to deal with additional questions or confusion in these areas will be important in establishing a good relationship with participants. Some service providers felt that interviewers should be unrelated to participants. Some also noted that 'debriefing' skills could be crucial when participants have experienced stillbirths, miscarriages or had children placed in care.

All interviewers need to be able to conduct interviews in a welcoming, appropriate and non-threatening environment. Service providers felt strongly that skilled Aboriginal people (for example health workers or midwives) with knowledge about the availability of services would be the most effective interviewers. If interviewees then opened up about issues during the process, interviewers needed broader awareness about health, literacy, counselling and other support services.

Aboriginal community members thought it was more important to provide a choice between an Aboriginal and non-Aboriginal interviewer. This group valued the notion of a range of interviewers – for example health workers, midwives and Indigenous Cultural Consultants. Of significance to all those involved in the consultation was having an interviewer who had good community connections, knowledge and an understanding of local politics.

Both service providers and community members felt that if interviewers were able to establish trusting relationships with participants and reassure them about confidentiality, it is more likely that women will respond to sensitive questions. Given that many Aboriginal women have bad experiences in hospitals where racism has been a key factor, interviewers must recognise this, but also ensure that participants are informed about the potential for this study to help improve services in the future. It was suggested that interviewers needed to be advocates for the study and able to explain how the research can be helpful to improving services.

What questions/topics should be included in the study?

The following research questions and topics were suggested by **Aboriginal community members**:

About your life during pregnancy

- Transport is a big issue, especially for those women how have already got a few kids and they have to catch the bus
- Dads need to be involved
- Did you need help with transport?
- Do you have other children at home that need to be looked after while you go to antenatal appointments? (sometimes its hard for me to go to appointments – so having a service where someone looks after the kids would be good)
- What support mechanisms did you have when you left hospital with your baby? Did you know where to go for support if you needed it?

About your pregnancy

- Did you go to antenatal appointments? If so, where did you go?
- Were you satisfied with the care you received?
- Were there any reasons that stopped you from attending antenatal appointments?
- What would encourage you to attend antenatal appointments?
- Would you be happy to have someone with you at your antenatal appointments?
- Were you able to build up a trusting relationship with a health worker at your antenatal appointments?
- At antenatal appointments were you given an information pack that included brochures about what to expect during your pregnancy?
- Were you disrespected or treated badly while attending antenatal appointments? If so, by who and where?
- Did you receive reminder calls for antenatal appointments?
- Were you asked if you would like to have a health worker come to your home for antenatal appointments?
- Were you given information about breathing techniques and pain relief methods at antenatal appointments?
- Were you given information about services available?

Labour and birth

- Was your partner able to be present at the birth?
- What type of birth did you have?
- Did you feel that the midwife was condescending?

- Were you given information about breathing techniques and pain relief methods while you were at the hospital?
- Did you feel you were in control of your pregnancy?
- Were you asked if it was alright for other doctors to come into your room when you were in labour?

About the first few weeks after the birth

- Were you advised that you would receive a home visit from a midwife?

About life with a new baby

- How empowered did you feel after leaving the hospital to go home?
- Were you asked about your understanding of postnatal depression?
- Did someone explain to you why some mothers get depressed after birth, and how to handle it if you do?
- Will you need ongoing support after baby is born and if so do you know where to go for support?

Other Comments

- Tick boxes don't really tell you much.
- Dedicate a few pages of the survey for storytelling.
- Need to highlight good experiences as well as poor ones.

The following research questions were suggested by **people in service delivery**:

About your life during pregnancy

- Who did you tell/when/why that you were pregnant?

About your pregnancy

- How often did you attend antenatal care?
- Where did you attend antenatal care and why?
- If you did not attend please explain why and what would encourage you to attend?
- What relevance do you place on antenatal care?
- What kind of antenatal care would you like and where?
- Who would you like to provide you with antenatal care?
- At antenatal appointments were you given information about breathing techniques and pain relief methods?
- Were you satisfied with the antenatal care you received?
- How can we help you structure your care?
- What can service providers do to help build trust?
- Did you receive information that was helpful to you?
- What information would have been useful for you to know that you were not given?

Labour and birth

- Where did you have your baby?
- At the hospital did a midwife or nurse ask if you or your partner is Aboriginal or Torres Strait Islander?
- Did you feel as though you were in control of your pregnancy, in labour and after baby was born?
- Did you give birth in a Baby Friendly Health Initiative (BFHI) accredited facility?
- Were you asked about the cultural needs of yourself and your baby?
- Were your cultural needs met while you were in hospital?
- Please describe your experience with the midwife.
- Did you receive information about birthing techniques and pain relief methods?

About infant feeding

- What feeding methods did you use?
- Did you breastfeed at all? If so how long for? Why did you stop?
- Was your breastfeeding support adequate?
- Who did you use for breastfeeding support and how did you find out who to contact?
- If applicable, at what age did you introduce solids and what were the solids? (The feeding method may have an impact on the type of postnatal support they try to access).

About the first few weeks after the birth

- Was your baby re-admitted into hospital? Did you know why?
- Did you know about the 24hr health advice call centre?
- Please describe the care you received over-all? Were you satisfied with the care you received?

About life with a new baby

- What did you know about postnatal depression before you had your baby? Did you know what to do if you got depressed?
- How empowered did you feel after leaving the hospital to go home?

Some questions about you and your household

- Tell us a bit about you?
- What community do you come from?
- What language do you speak?
- Did you need help with transport?
- Do you need anything else apart from traditional services?
- On a scale of 1-10 where do you see drugs and alcohol as an issue/problem in your life?

Dissemination and informing service delivery

Overall, and most importantly, both Aboriginal and non-Aboriginal community members and service delivery providers stressed the need for timely dissemination of information about the research results, and implementation strategies to transfer the information into practice. They also stressed the need for adequate resources to support these processes and ensure sustainability.

It was also noted that there are processes already taking place, such as Healthy for Life, and roll out of the Anangu Bibi model by Country Health SA, which may enable the research to be incorporated into service delivery.

Other initiatives and projects

While it was beyond the scope of this report to provide exhaustive detail about maternal and infant health initiatives already in place, in the Adelaide metropolitan area, a number of programs, projects and policies were mentioned during consultations which the Aboriginal Families Study will need to take into consideration. This section very briefly describes some of these and provides links for further information.

- **Healthy for Life** (<http://www.health.gov.au/healthyforlife>) is a Commonwealth Government initiative from the Department of Health and Ageing which aims to improve the health of Aboriginal and Torres Strait Islander people by enhancing the capacities of primary health services. Maternal and infant health is one of a number of focal areas of the initiative. There are many Healthy for Life Sites across Australia - the Adelaide metropolitan site has Nunkuwarrin Yunti of South Australia Inc as the lead agency in partnership with the Central Northern Adelaide Health Service (CNAHS), the Children, Youth and Women's Health Service (CYWHS), the Southern Adelaide Health Service and the Aboriginal Sobriety Group. This site has the aim of developing a model for Aboriginal maternal health care that can be used across all service providers and to date activities have included auditing maternal care services against best practice, with an aim to implement quality improvement initiatives in the next stages of the project.
- **Universal nurse home visits and the Family Home Visiting** initiative from CYWHS (www.cywhs.sa.gov.au). All families across South Australia receive one home visit within the first few weeks of their child's life. Where the visit is to the family of an Aboriginal child, an Indigenous Cultural Consultant will accompany the nurse on this, and potentially subsequent, visits. During the universal contact visit, caregivers complete the Pathways to Parenting Questionnaire which includes psychosocial and health information about the child, caregiver and family. Those families identified with additional needs for support, at this first visit, may be offered ongoing Family Home Visiting up to the child's second birthday. The program involves up to 34 visits focusing on child health and development and maternal-child attachment. The visits take place weekly for the first six weeks, then fortnightly for the next six months. Families receive monthly visits for the final twelve months of the program, and are supported in forming links with their local community. The evaluation strategy for the Family Home Visiting program includes qualitative and quantitative research programs focusing on service provision to Aboriginal families in the Adelaide metropolitan area (this project was completed in 2008) and a broader evaluation of the program by a research team led by Professor Michael Sawyer from the University of Adelaide and the Women's and Children's Hospital.

- The **South Australian Pregnancy Record** (also called the “Hand-held Pregnancy Record” or the “Orange Book”; <http://www.dh.sa.gov.au/pehs/pregnancy-record.htm>) – is designed to accompany women throughout their antenatal care and contains notes made by health providers and women during their pregnancy, delivery and in the early postnatal period. After the birth of the child, the original document gets placed in the mother’s medical records. The record includes details from public and private health care providers and includes information about smoking and alcohol.
- **Footprints in Time**, the Longitudinal Study of Indigenous Children (http://www.facs.gov.au/internet/facsinternet.nsf/research/ldi-lsic_nav.htm) is a mixed-method longitudinal research project tracking the development of Aboriginal and Torres Strait Islander children from a range of sites across Australia. In 2008, the project involved interviews with parents of two cohorts of children (6-to-18 months and 3.5-to-4-year olds) in Adelaide (and other sites across Australia) and will examine the factors that contribute to positive development and resilience in Aboriginal children.
- The Australian Bureau of Statistics is currently conducting the **National Aboriginal and Torres Strait Islander Social Survey** (NATSISS; <http://www.abs.gov.au/>) with an aim to complete data collection by the end of November 2008 and information available in Sept 2009. The Communities were randomly selected with a target sample for the project of 10,000 Aboriginal and Torres Strait Islander people across Australia, and this administration of the survey will include children under 15 years. The survey will examine a wide range of areas of social concern including health, education, culture and employment. Interviews will be conducted by trained ABS interviewers, with multiple informants per household in both remote and non-remote areas.
- The evaluation of the **Southern Aboriginal Maternity Care Project** was released in 2008 (<http://www.sapo.org.au/pub/pub11923.html>). This research examined a pilot project located in the Southern metropolitan area of Adelaide which looked to develop an integrated maternity service delivery model for Aboriginal and Torres Strait Islander women and their babies. The report details the evolution and implementation of the service model developed by the Southern Adelaide Health Service in partnership with the Department of Health.

7. Next steps: moving on to phase 2

Developing the research protocol and interview schedule

Towards the middle of 2008, the research team started drafting a research protocol for phase 2 of the project based on feedback from the consultations.

The research protocol covers:

- aims and research questions identified through the consultations
- issues to be covered in the research
- a detailed research plan covering methods for inviting women to take part, confidentiality procedures, and what will be involved for women participating in the research
- procedures for developing and piloting of an interview schedule/questionnaire
- procedures outlining how data will be analysed and what steps will be taken to ensure that data are interpreted appropriately
- community engagement strategies
- dissemination and feedback to communities taking part.

The draft protocol was reviewed by members of the research team at a two day workshop in Adelaide in June 2008, and then further refined, before being circulated to members of the Advisory Group in July. Work on a draft interview schedule also commenced around this time.

The Advisory Group has reviewed and commented on several drafts of the research protocol and interview schedule. We are continuing to work with the Advisory Group to review and revise both documents. Pilot testing of the interview schedule will occur in the first half of 2009 prior to commencing the interviews later this year.

It is envisaged that the research will involve interviews with over 500 women having a baby over a 12 month period in 2009/2010. Interviews will be conducted in regional, rural, remote and urban parts of South Australia.

Funding for phase 2

The original grant from the National Health and Medical Research Council covered the consultation phase and provided a small amount of funds to support the conduct of interviews. Additional funds are required to implement the research in ways that are consistent with the feedback from the consultation.

In late 2008, funding applications were submitted to:

- the Rio Tinto Aboriginal Fund
- the National Health and Medical Research Council (NHMRC)

The application to the NHMRC included in-kind commitments to support the research from the MCRI, UniSA and SGRHS, CYWHS, County Health SA, and AHCSA. The South Australian Department of Health has committed to a cash contribution to the research if the NHMRC application is successful.

We have already been notified that our application to the Rio Tinto Aboriginal Fund requesting funding to cover community engagement and recruitment strategies had been successful. Funds will be available from March 2009. The outcome of the NHMRC application will not be known until June 2009.

Next steps

Approval of the AHCSA Board and AHCSA Ethics Committee

Before we can proceed to phase 2 of the project we need the approval of the AHCSA Board. We also need to obtain approval from the AHCSA Human Research Ethics Committee and other institutional ethics committees. Applications to ethics committees will be submitted in April 2009.

Broadening the Partnership

Phase 1 of the project involved a partnership between MCRI and the AHCSA working in collaboration with UniSA and the SGRHS. In phase 2, it is proposed to extend the partnership to include: the Department of Health SA, CYWHS and Country Health SA. A major reason for expanding the partnership was to engage policy makers in the research, with the aim of ensuring that the study findings are used by policy makers to inform future service development for Aboriginal families.

Phase 2 of the project will require drafting of a new partnership agreement. It is proposed that this take the form of:

- a *Memorandum of Agreement* to be signed by representatives of the AHCSA, MCRI, UniSA and SGRHS, Department of Health SA, CYWHS and Country Health SA
- a *Code of Research Ethics* for the project outlining guiding principles, obligations of the partner organisations and ways of working together to conduct the research.

Feedback to communities

Feedback to communities and organisations taking part in the consultation will be via distribution of flyers, newsletters and development of a project website. Community engagement in the research will also occur via the Aboriginal project officers returning to communities that participated in the consultation to invite women to take part in the research.

8. References

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9. Appendices

Appendix 1.	Aboriginal Advisory Group Members and Terms of Reference
Appendix 2.	Consultation questions
Appendix 3.	Flyer: Aboriginal Families Study in South Australia
Appendix 4.	Frequently Asked Questions
Appendix 5.	Publicity about the Aboriginal Families Study

Appendix 1. Aboriginal Advisory Group Members and Terms of Reference

Members

- Jackie Ah Kit (until August 2008)
- Brian Butler
- Alwin Chong
- Harriette Coleman
- Glenise Coulthard (from August 2008)
- Karen Glover (Chairperson)
- Margaret Hampton (from August 2008)
- Sharron Williams/Rebecca Kimlin

Terms of reference

The role of the Aboriginal Advisory Group is:

1. To provide advice and direction to the research team regarding:
 - planning and conducting consultations
 - culturally appropriate recording and reporting of consultation findings
 - strategies and opportunities to identify and facilitate engagement with Community members, organisations and other relevant Aboriginal and Torres Strait Islander groups.
2. To provide input and guidance for the research team to identify and employ successful culturally appropriate behaviour and competence.
3. To identify and facilitate (where appropriate) engagement opportunities for the research team with community controlled health services, community members, organizations and other relevant parties including policy makers.
4. To provide advice and guidance to the research team regarding development of study methods and procedures for data collection in phase 2.
5. To identify mechanisms that will best support and enable the research team to appropriately undertake consultation and research activities, including defining the role, responsibilities and terms of reference for a project advisory group for phase 2 of the study.
6. To make recommendations to the AHCSA and the Healthy Mothers Healthy Families research group regarding proposed study methods and procedures for data collection in phase 2 of the study (based on the outcome of consultations in phase 1).

Appendix 2. Consultation questions

Aboriginal Families Study Consultation

Date and location	
Present	
Project Officer/ Research team members present	
Actions	

<p>Background</p> <p>The Healthy Mothers Healthy Families Research Group (Murdoch Childrens Research Institute) in partnership with the Aboriginal Health Council of South Australia (AHCSA) is planning a research project about pregnancy, birthing and postnatal care for Aboriginal families in South Australia. During late 2007 and early 2008 the South Australian project team will be consulting with Aboriginal communities, organisations and groups throughout South Australia.</p> <p>We are interested in your views about</p>
<p>1. Whether a study about pregnancy, birthing and postnatal care for Aboriginal families is needed?</p>

2. What issues/topics should be included in the study?

3. What information would be most valuable for us to collect? What would help Aboriginal communities and community organisations in advocating for better services for Aboriginal women and families?

4. What are the best ways to inform Aboriginal women and families about the study? (e.g. via Aboriginal health services, via community and family (kinship) networks, via Aboriginal hospital liaison officers/Indigenous cultural consultants, via community newsletters, other methods)

5. How do we engage young women (under 18) to take part?

6. What are the best ways to collect information in the study? (e.g. interviews, paper-based self completion questionnaires, telephone interviews, on-line self-completion questionnaire, group-based interviews/focus groups, other methods)

7. How should participants be reimbursed for their time?

8. How should information gathered in the study be reported back to participants, to community organisations and to community members? (e.g. project newsletters, website, community meetings, other methods)

9. What needs to happen/what do the researchers need to do to ensure that there is community control and ownership of information?

Other comments/issues

Appendix 3. Flyer: Aboriginal Families Study in South Australia

The Healthy Mothers Healthy Families Research Group (Murdoch Childrens Research Institute) in partnership with the Aboriginal Health Council of South Australia (AHCSA) is planning **a research project about pregnancy and postnatal care for Aboriginal families in South Australia.**

The project is called the **Aboriginal Families Study**. It is a sister study to a state-wide postal survey of recent mothers (called the Healthy Mothers Healthy Families Survey) that is being carried out in South Australia and Victoria in early 2008.

What is the project about?

To find out what Aboriginal women and women with an Aboriginal partner having a baby in South Australia think of their pregnancy care, care during labour and birth, and care after the baby is born.

What is the aim of the project?

- To use the information to advocate for changes to improve pregnancy, birthing and postnatal services for Aboriginal women and families.
- To advocate for increased resources for Aboriginal community controlled health services and inform government about the needs of Aboriginal communities.

What we want to find out at this stage of the project?

- We are interested in community views about how information should be gathered.
- How we should go about informing and inviting women to take part.
- What issues/topics should be included in the study?

How the project will be conducted

During late 2007 and early 2008, the project team will be consulting with Aboriginal communities, organisations and groups throughout South Australia. We are hoping to talk to as many organisations and community members as possible so that your ideas and comments can be used to shape the research methods and plans for the study.

Once we have gathered this information, it will be summarised and used to develop a plan for the research phase of the project (2008-2010). The study (phase 2) will only go ahead if there is community support demonstrated during the consultation period (phase 1).

Who will conduct the project?

An Aboriginal Advisory Group with representation from metropolitan and regional health services, the Aboriginal Health Council of South Australia, Aboriginal family and support services, and Aboriginal health workers with technical expertise in maternity and postnatal care, has been formed to guide and advise the project team. Project staff will be promoting the project and consulting communities and organisations in South Australia.

How to contact us:

Roxanne Miller is based at the Spencer Gulf Rural Health School in Port Lincoln and will be working with communities in Port Augusta, Port Lincoln, West Coast, Spencer Gulf, Mid North and York Peninsula, Ceduna, Coober Pedy, Yalata and Oak Valley.

T: (08) 8302 2524

E: roxanne.miller@unisa.edu.au

Hayley Wilson and Fiona Arney are based at the Magill Campus, University of South Australia and will be working with communities in Adelaide, Murray Lands, Riverland, Point Pearce, Point McLeay and Mt Gambier.

T: (08) 8302 4164 or (08) 8302 4172

**E: hayley.wilson@unisa.edu.au or
fiona.arney@unisa.edu.au**

Formal agreement of the AHCSA will be obtained to include information from the study in any written report

Appendix 4. Frequently Asked Questions

Frequently Asked Questions

Q. I have heard that there are a number of studies of Aboriginal early childhood taking place – how does this fit in?

A. This research study focuses on mothers with the aim of improving services available to them and giving babies the best start to life.

Q. What kind of questions will you be asking?

A. The questions are guided around the research study and what issues should be included, what information would be most valuable, what services would help Aboriginal communities and organisations and what are the best ways to inform people about the study.

Q. How long will it take?

This depends on how many people attend the consultation, how much time you have and how much information you are willing to give.

Q. How much involvement do you want from us?

A. Only one visit is necessary to complete the consultation and the more information we receive the better it will be for the research study and the Aboriginal community.

Q. What if I can't get to the consultation session – how can I give my feedback?

A. You can contact project staff by phoning or you can e-mail us your feedback – please refer to project officers contact details below or contact details on flyer.

Q. Do we have to take part?

A. You are not required to take part, however, your feedback is important to us and would be appreciated.

Q. How will information from the study be interpreted and how can I find out the results of the project?

A. It is envisaged that a written report of the study will be made available to participants, community organisations and community members on completion through means such as project newsletters, the project website and community meetings.

Q. How will contact with us be maintained?

A. We have your original details that you gave at the start of the consultation. You can also contact Hayley Wilson on (08) 8302 4164 or email hayley.wilson@unisa.edu.au to give any change of address details.

Q. What will happen in phase 2 of the project?

A. Detailed plans for phase 2 of the project will be formulated drawing on feedback and community views expressed during the consultations. The Advisory Group will be guiding and advising the project team in developing appropriate methods and plans for how the research will be carried out.

The study (phase 2) will only go ahead if there is community support demonstrated during the consultation period (phase 1).

Q. How will the privacy and confidentiality of people taking part in the research be protected?

A. The project will be undertaken in accordance with the National Health and Medical Research Council (NHMRC) Guidelines for the Ethical Conduct of Research in Aboriginal and Torres Strait Islander Health Research.

Please contact us if you would like more information on the procedures to protect the privacy and confidentiality of participants and their feedback.

Q. What will researchers do to ensure that there is community control and ownership of information?

A. The research team is committed to the principles and philosophies underpinning Aboriginal community control and ownership of information arising from collaborative research. That is community initiated, community based and community controlled research that promotes self determination, respect and recognition of Aboriginal peoples having the right to control local issues and solutions.

Analysis and interpretation of the findings will be done in consultation with the project Advisory Group.

No information from the study will be included in any written report without formal agreement from the AHCSA.

Q. What if I want more information?

A. Please contact a member of the research team:

Study Investigators

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Appendix 5. Publicity about the Aboriginal Families Study

- Kura Yerlo Open Day 2nd November 2007 - Angela Sloan attended.
- South Australian Aboriginal Women's Gathering November 2007 - Angela Sloan attended.
- Apology event 13th February 2008 - Fiona Arney and Hayley Wilson attended.
- Turkindi meetings - project represented at regular meetings since 5th March 2008 and Fiona Arney and Hayley Wilson hosted the April meeting.
- Meeting between Hayley Wilson and Fiona Arney (UniSA), Ivan Copley (Australian Bureau of Statistics), Alwin Chong (AHCSA), Jess – Research Administration Officer - (FaHCSIA, Footprints in Time study) 12th March 2008 at AHCSA.
- Taoundi College Health Open Day 22nd May 2008 -Hayley Wilson attended.
- Alwin spoke at HDA Research Day about the project on the 23rd May 2008.
- Reconciliation event 1st June 2008 -Fiona Arney attended and provided information about the study on the Turkindi stand.
- Indigenous Cultural Consultants meeting 11th August 2008 - Karen Glover and Hayley Wilson attended.
- Trip to Central Australia with representatives from Australian Bureau of Statistics and the Australian Red Cross, visits with Desert Knowledge in Alice Springs, Nganampa Health Council, and two Homemaker Services on the APY Lands.

