Evaluation of the Project:
The Journey of Aboriginal Children and their Families throughout the Northern Child Health Network

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Abbreviations Table

HNE – Hunter New England Local Health District
NNSW – Northern NSW Local Health District
NCAHS – North Coast Area Health Service
AHLO – Aboriginal Health Liaison Officer
LHD – Local Health District
CYPFS – Children, Young People and Family Services.
JHCH – John Hunter Children's Hospital

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Abstract

An evaluation was conducted of the Hunter New England and Northern NSW Local Health Districts' Aboriginal children and family's project. This project aimed to gain insight to improve the journey of an Aboriginal child and their family after a decision is made to transfer a child to a higher level of care outside their local community. The evaluation aimed to assess the effectiveness of the project and to make a contribution to organisational learning about cultural change. The evaluation questions were:

1. Were the project objectives met?
2. Have the solutions been implemented?
3. Is there a difference in the Aboriginal patient and family experience?
4. Do Aboriginal staff detect a difference in the workplace?
5. Do non Aboriginal staff detect a difference in the workplace?
6. If a difference in the workplace is detected, what were the critical success factors that brought about this change?

Nine Aboriginal family and 27 key stakeholder interviews were conducted. A thematic analysis found that the project objectives were partially met, that most solutions were implemented to varying extents and improvements were detected by staff. Analysis of Aboriginal family interviews showed that they were happy with the care provided but that transport remained an issue across both health services. In Hunter New England LHD there was greater spread and sustainability of the strategies implemented, but there was more family stress related to the journey than in Northern NSW LHD. Cultural Respect training had not yet reached many of the ward staff in HNE. This was suggested to be a major reason why change was not so apparent at the ward level. In Northern NSW there had been flexible Cultural Awareness training for clinical staff and good relationships built between non-Aboriginal staff and Aboriginal Hospital Liaison Officers. Recommendations for the future were made.

Keywords: Aboriginal, travel, accommodation, cultural respect, evaluation

Executive Summary

Introduction

The Northern Child Health Network commenced a project in June 2008 involving Hunter New England Health (HNE) and the North Coast Area Health service, now the Northern NSW Local Health District (Northern NSW). The Aboriginal children and their families and carers project was a collaborative project which aimed to gain insight to improve the journey of an Aboriginal child and their family after a decision is made to transfer the child's health care from a lower level of care in their local community, to a higher level of care outside their local community. An evaluation of this project was conducted over 2011 and 2012. The aim was to evaluate the effectiveness of the solutions in achieving the project objectives and to contribute to organizational learning about cultural change. The primary evaluation questions were:

1. Were the project objectives met?
2. Have the solutions been implemented?
3. Is there a difference in the Aboriginal patient and family experience?
4. Do Aboriginal staff detect a difference in the workplace?
5. Do non Aboriginal staff detect a difference in the workplace?
6. If a difference in the workplace is detected, what were the critical success factors that brought about this change?

Method

The evaluation was conducted separately within each service using the similar approach to the original project and then commonalities and differences were reviewed. An Evaluation Governance Committee was established to provide oversight and direction. Two project officers, one from HNE and one from NNSW who were not involved in the project design or implementation conducted the evaluation under the Clinical Education and Training Institute Rural Capacity Building Program.

Nine interviews were conducted with Aboriginal families who had a recent experience with the health system and had travelled away from their local community to access a higher level of care. Five families from Casino or Tabulum who travelled to Lismore and four families from Moree or Tamworth who travelled to Newcastle participated. The families were selected by local Aboriginal Health Care Workers.

Fourteen staff from HNE and 13 staff from Northern NSW who had key roles in the project were interviewed as key informants. These participants were identified by senior managers in each health service as project leaders. A total of 10 interviewees were Aboriginal staff, five in each local health district. The participant interviews used a semi structured approach with open ended questions and included a survey to assess perceptions regarding whether the project objectives were met and whether solutions were implemented. A thematic analysis of the family and key stakeholder interviews was conducted. Each health service was analysed separately then common themes were reviewed. Scores for the implementation

assessment scores and perceptions regarding success in meeting project objectives were collated and tabulated for each health service separately.

Ethics approval was obtained from both the Hunter New England Human Research Ethics Committee and the Aboriginal Health & Medical Research Council Ethics Committee.

Results

Overall, most staff in Northern NSW perceived that the project was either effective or very effective in meeting the objectives. "Provide cultural knowledge to children's health planning" was rated the least effective in Northern NSW but rated highly effective in HNE. The objective of "identifying involvement of Aboriginal families in discharge planning" was rated as least effective in HNE but rated more highly in Northern NSW.

Most strategies were partly implemented and most staff detected a difference in care provided to Aboriginal people. Cultural Respect Education in HNE and Cultural Awareness training in Northern NSW along with enhancements to the physical environment were rated the highest as strategies that were either fully or partially implemented. A higher percentage of Aboriginal staff detected a change compared to non-Aboriginal staff in both health services.

Positive themes across both LHD's included a cultural shift in children's services and the families reported that they felt they received good care by competent staff. The common theme across both services was that families who had a lot of contact with AHLO's had a much more positive experience than those that did not have that contact. The implementation assessment also showed that the recommendation to review AHLO services was not implemented.

The main finding for both LHD's where there was not a positive improvement resulting from the project was in discharge planning processes, including the organisation of transport. Even though 77% of staff interviewed in NNSW reported that improved discharge planning had been implemented, the difficulty of obtaining transport home is the common theme for families.

The Cultural Awareness (NNSW) and Cultural Respect (HNE) training were found to be the main changes that led to attitudinal shifts and in both areas resulting in action being taken to improve the experience of Aboriginal families travelling for care. This appeared stronger at the ward level in Northern NSW where flexible cultural awareness training had been delivered to clinical staff by a highly respected AHLO. This AHLO had also worked with the Aboriginal community to support people to speak up more. In HNE the cultural changes were more systemic and actions more visible at Executive and senior managerial levels where Cultural Respect Education had been targeted.

In HNE, where the approach to cultural change was organisation wide with strong Executive leadership, there was found to be a greater level of sustainability and spread of the improvements. Strategies for change appeared to be more embedded within planning for

children's services. The commitment of the frontline managers and the Aboriginal staff was critical in leading the changes in Northern NSW.

The other factors found to be critical for change were involvement of Aboriginal Hospital Liaison Officers with families, collaboration, communication processes and resources to support implementation. The Collaborative partnerships were important but reported as being difficult and hard work.

Recommendations

The following recommendations are made based on the findings of this evaluation.

1. Senior executive leadership develop and support a process to embed the strategies that were implemented and found to be effective but were not sustained and assess the continued relevance of strategies that have yet to be fully implemented from the project.
2. Consideration is given to implementing more widely the flexible approach taken in Casino for cultural awareness training delivered by a respected Aboriginal Hospital Liaison Officer to ward based clinicians. This model was reported as having a very positive impact by both the local Aboriginal staff and the clinicians.
3. In order to improve communication, build relationships and build cultural competence, it is recommended that Aboriginal Hospital Liaison Officers are trained to participate in cultural respect or cultural awareness training at local sites.
4. It is recommended that the strategy from the project to review and extend AHLO hours and gender mix be reconsidered as support from an AHLO was a critical factor for Aboriginal families to have a positive experience when travelling for a higher level of care.
5. Improve the dissemination of the 'Patient Information Guide' to families travelling for care to John Hunter Children's Hospital. Aboriginal families in HNE requested that a handbook is made available to understand what resources are available, including accommodation and AHLO contact details. Although this handbook is on the Kaleidoscope website, it is difficult to find and not reliably disseminated to families. The Directory of Services in NNSW requires a process to keep it updated.
6. As transport home and involvement in discharge planning was one of the main issues for Aboriginal families, it is recommended that clearer transport options are given to families well in advance of discharge. The involvement of the AHLO in planning for the travel home is pivotal to the experience of the family.
7. A positive outcome from the project was the enhancement of physical environment of the health services. Aboriginal families acknowledged that artworks, flying the flags and seeing photos of family and friends from their community contributed to the level of comfort and welcome they felt when accessing the health services. It is recommended that the health services continue to support the improvement of the physical surroundings throughout the health services to acknowledge the traditional owners of the land.

Introduction

The Northern Child Health Network commenced a project in June 2008 involving Hunter New England Health (HNE) and the North Coast Area Health service, now the Northern NSW (NNSW) Local Health District. The Aboriginal children and their families and carers project was a collaborative aimed at gaining insight to improve the journey of an Aboriginal child and their family after a decision is made to transfer the child's health care from a lower level of care in their local community, to a higher level of care outside their local community.

The objectives were to:

- Confirm what constitutes a culturally appropriate health service for Aboriginal children and their families;
- Explore communication between hospital staff and Aboriginal children and their families;
- Identify the level of involvement Aboriginal children and their families have in health care and discharge planning;
- Identify what support and assistance is required for Aboriginal families when their child's health care is transferred to a service outside their local community, in particular travel, accommodation and social support arrangements;
- Build on existing initiatives so that the best possible and culturally appropriate supports are accessible to Aboriginal families when their child's health care is transferred to a service outside their local community;
- Provide cultural knowledge to children's health planning to ensure improved health experiences and outcomes for Aboriginal children.

Project Officers supported the implementation of strategies to address identified issues in each health service until the end of June, 2009 in NNSW and June 2010 in HNE. An evaluation of the project has now been conducted and the report of findings made to the Northern Child Health Network and the two Local Health Districts of HNE and NNSW.

Background

Closing the Gap for Aboriginal and Torres Strait Islander people is a priority for HNE, NNSW and the Northern Child Health Network. In 2007, Closing the Gap[1] data reported that Aboriginal and Torres Strait Islander children were almost five times as likely to die than non-Indigenous children before the age of five and that 13% of Indigenous babies born in Australia were of low birth weight – more than double that of low birth weight babies in Indigenous populations in Canada and the USA, and more than 60% higher than the number of low birth weight Indigenous babies born in New Zealand.

In the New South Wales North Coast region, the Indigenous population is younger than the non-Indigenous population with 42% of the Aboriginal population aged 14 years or less compared to 21% of non-Aboriginal children[2]. Two Ways Together[3] reported around 28% of

Aboriginal households in the region were single parent families compared to 13% for non-Aboriginal households and *"between 2002 and 2004, 14% of Aboriginal babies in the North Coast region were born with low birth weight. This is the second highest figure in the State after New England/North-West and it is 125% higher than for non-Aboriginal babies throughout the State." (p15-16)*. In the HNE region, the Indigenous population is younger than the non-Indigenous population with Aboriginal children and young people represented 5.8% of the total population of children and young people and 51% of the Aboriginal population[4]. In the New England/North-West region, 80% of Aboriginal households have dependent or non-dependent children compared to 59% of non-Aboriginal households and 47% of Aboriginal children in the region were living in poverty in 2001[5].

Given these health gaps, the level of poverty and the need for Aboriginal families who live in rural areas to travel out of their communities to access higher levels of care, the Aboriginal children and their families and carers project was undertaken. The new vision was that Aboriginal children and their families feel culturally safe and well supported after a decision is made to transfer the child's health care from a lower level of care in their local community to a higher level of care outside their local community.

The scope of the project for HNE was families travelling between Moree and Newcastle or Tamworth, or travelling between Tamworth and Newcastle. In NNSW the scope was families travelling between Casino and Lismore. The project built on the extensive consultation and existing initiatives from recent Aboriginal Health plans and projects. Interviews were conducted with 18 families who had their child transferred to a higher level of care in the 12 months prior to the commencement of the project. A further 31 stakeholder interviews and 8 focus groups acute and community networks and Aboriginal Medical Services were conducted. The main opportunities for improvement identified in the project are shown in Appendix 1. A range of strategies were recommended to improve the experience for Aboriginal families as shown in Box 1 below with details in Appendix 2. The plan was to design and implement the strategies over a two year period. One Aboriginal project officer in NNSW and one non-Aboriginal project officer in HNE supported the project for the first 12 months. Two project officers in HNE, one Aboriginal and one non-Aboriginal, then supported implementation in HNE while this was managed by staff in existing services in NNSW. Direction was provided by a Collaborative Steering Committee. An evaluation has now been conducted. The aim was to evaluate the effectiveness of the solutions in achieving the project objectives and to contribute to organisational learning about cultural change. The primary evaluation questions were:

1. Were the project objectives met?
2. Have the solutions been implemented?
3. Is there a difference in the Aboriginal patient and family experience?
4. Do Aboriginal staff detect a difference in the workplace?
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Box 1. Definitions of the Recommended Project Strategies

1. Increased Cultural Competence of Staff

Definition: A workforce that is culturally competent in creating and maintaining a culturally safe environment for Aboriginal People accessing acute services.

2. Improved Collaboration within and across services

Definition: An infrastructure that performs in a coordinated way to care for Aboriginal children and their families. Aboriginal Health, hospital and community staff work collaboratively to develop cultural security for Aboriginal people accessing health care.

3. A Physical Environment that visibly recognises Traditional Owners of the land

Definition: An environment that physically appears less foreign to Aboriginal people, designed in a way that encourages access and is enhanced by staff that are confident and competent in engaging with Aboriginal people.

4. Enhanced access to support

Definition: Improved processes that ensure Aboriginal families have timely and appropriate information on support available to them and access to staff that can assist with the process.

5. Improved Discharge Planning

Definition: Improved processes that involve families in the discharge plan and greater use of Information Technology.

6. Improved training and collection of data

Definition: Training for health staff that increases their understanding of the reason for accurate identification of Aboriginal children and their families and dispels myths. Information for Aboriginal families also encourages them to identify.

Methods

Design

The evaluation was conducted separately within each service using the similar approach to the original project and then commonalities and differences were reviewed. An Evaluation Governance Committee was established to provide oversight and direction. Two project officers, one from HNE and one from NNSW who were not involved in the project design or implementation conducted the evaluation under the Clinical Education and Training Institute Rural Capacity Building Program.

A summative and formative approach was undertaken to assess implementation progress and impact thus far as it is acknowledged that the project forms part of long term cultural change programs across both health services. The evaluation questions were developed using Program Logic as described in Figure 1. Program Logic provides a framework to evaluate projects as a function of the situation (what was it like previously), inputs (what went into the project), the outputs (the types of activities / participants involved in developing solutions) and the outcomes/impact (specific changes in behaviour, knowledge, skills, status and level functioning occurring as a result of project).

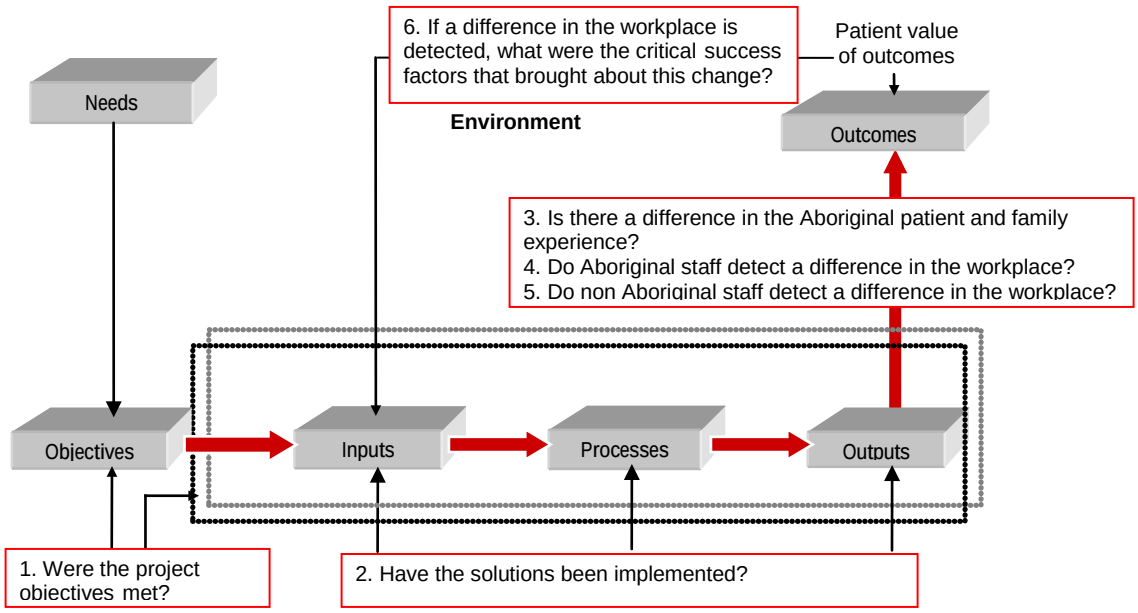

Figure 1: Program Logic Model – Journey of Aboriginal Children and their Families

The critical questions were answered by a mix of:

- document analysis to review the solutions and associated outputs;
- interviews with Aboriginal families who have had a recent experience with the health system at the project sites;
- key stakeholder interviews.

Participants

Aboriginal Family Interviews

Nine interviews were conducted with Aboriginal families who had a recent experience with the health system and had travelled away from their local community to access a higher level of care. Five families from the Casino area who travelled to Lismore and four families from Moree or Tamworth areas who travelled to Newcastle participated. The families were selected by local Aboriginal Health Care Workers. (Family Interview Questionnaire in Appendix 3 and Participant Information Statement Appendix 4).

Key Stakeholder Staff Interviews

Fourteen staff from HNE and 13 staff from Northern NSW who had key roles in the project were interviewed as key informants. These participants were identified by senior managers in each health service as project leaders. A total of 10 interviewees were Aboriginal staff, five in each local health district. A semi structured approach with open ended questions was used (Questionnaire Appendix 5) and included a survey to assess perceptions regarding whether the project objectives were met and whether solutions were implemented (Implementation Assessment Tool included in Appendix 2).

A thematic analysis of the family and key stakeholder interviews was conducted. Each health service was analysed separately then common themes and differences were identified by both reviewers. Scores for the implementation assessment scores and perceptions regarding success in meeting project objectives were collated for each health service separately.

Ethics approval was obtained from both the Hunter New England Human Research Ethics Committee and the Aboriginal Health & Medical Research Council Ethics Committee.

Results

Were the Project Objectives Met?

Overall, most staff in NNSW perceived that the project was either effective or very effective in meeting the objectives (Figure 2). "Explore communication…", "Identify…support and assistance…" and "Identify level of involvement in discharge planning" were rated the highest. "Provide cultural knowledge to children's health planning" was rated the least effective.

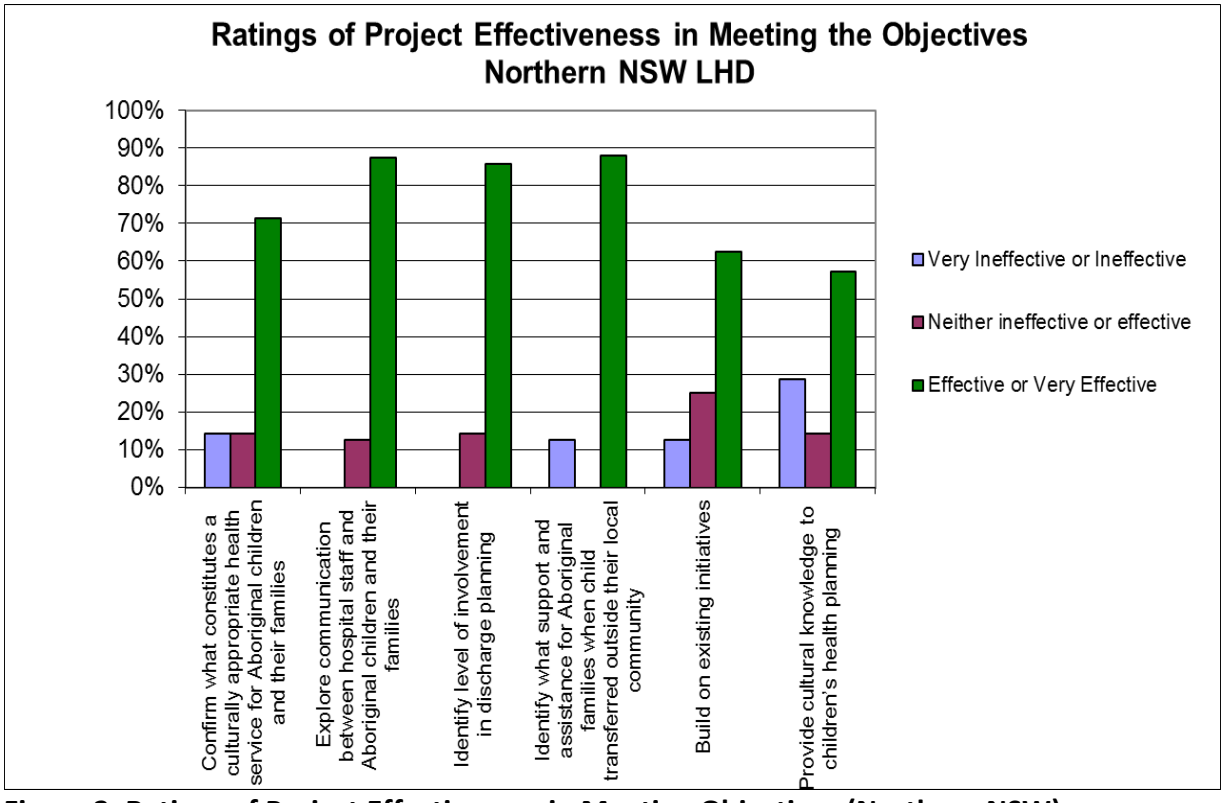

Figure 2. Ratings of Project Effectiveness in Meeting Objectives (Northern NSW).

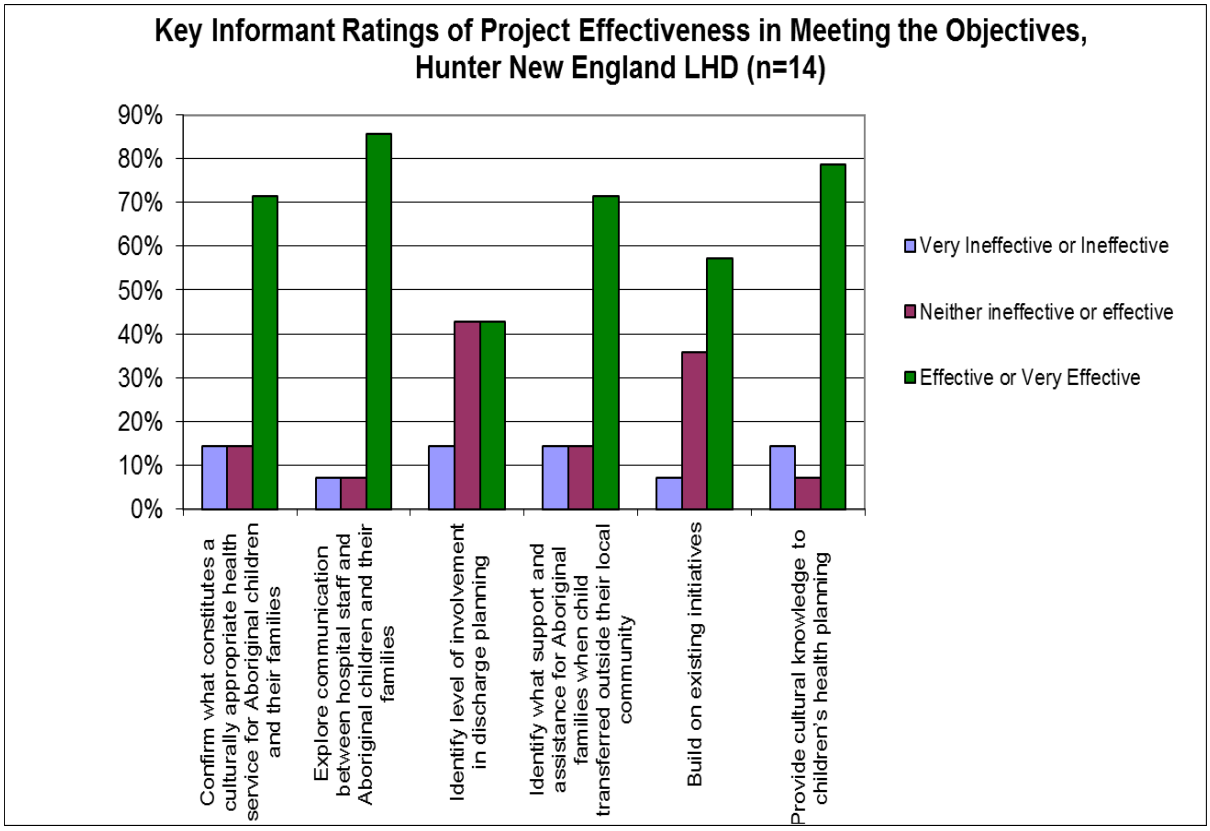

Figure 3. Ratings of Project Effectiveness in Meeting Objectives (HNE).

In HNE, although most key informants perceived that the project had met the objectives, the pattern was different in that "providing cultural knowledge to children's health planning" was rated highly effective while "identify involvement of Aboriginal families in discharge planning" objective was rated as least effective (Figure 3).

Have the solutions been implemented?

Northern NSW

There was strong agreement among the stakeholders that cultural awareness training and the physical environment solutions had been either fully or partially implemented. There was less agreement around Aboriginal Impact Statements, patient handbooks, extended hours for AHLO's, recruitment of Aboriginal staff and cultural issues included in education programs (Table 1). There were no solutions assessed as fully implemented by the stakeholders (Figure 4).

"…we did get the list of phone numbers - pamphlet with all the names and phone numbers and things – that was really good. That's a really helpful thing. Probably needs to be updated regularly so that we know that it's the right one. Even if it's done every one or two years, someone with the responsibility to read through it and check that all these numbers... And if there's something different we could add in. That's used throughout not just in paediatrics" Staff interview

Table 1. Northern NSW Implementation Assessment

Solution	Fully or Partially Implemented
Cultural Awareness Training	84.6%
Enhance physical environment	84.6%
Collaborative relationships	76.9%
Improve discharge planning	76.9%
AHLOs well informed	69.2%
"Speak Up" posters	69.2%
Directory of Aboriginal Services	61.5%
AHLO network forum	61.5%
Discharge summaries	61.5%
Retrain staff on Identification Guidelines	61.5%
Brochure for Aboriginal families	46.2%
Review space for family gatherings	46.2%
Standardised core roles AHLOs	46.2%
Cultural issues in education	38.5%
Recruit Aboriginal people	38.5%
AHLO services extend hours and both genders	30.8%
Patient handbooks	30.8%
Aboriginal Impact statements	23.1%

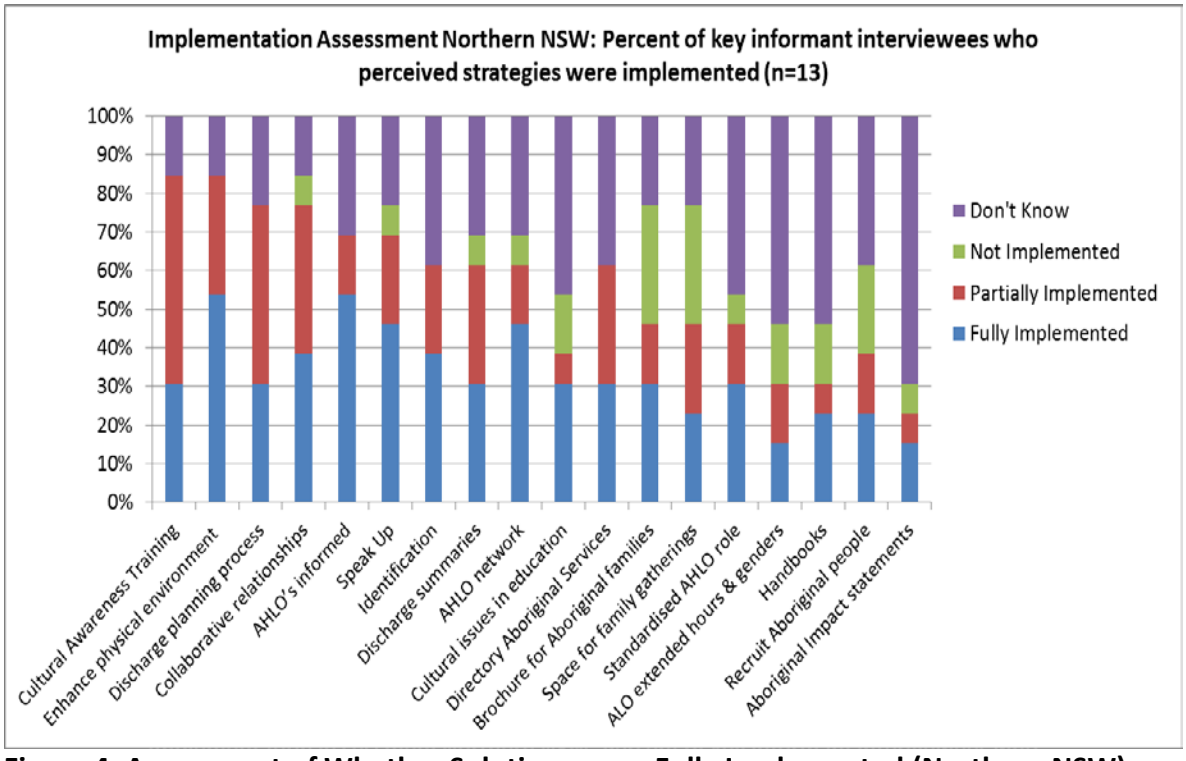

Figure 4. Assessment of Whether Solutions were Fully Implemented (Northern NSW)

Hunter New England

All HNE key stakeholders felt that the Cultural Respect Education, enhance physical environments and shuttle bus transfers from the train station strategies were fully or partially implemented (Table 2). Less than a third perceived that patient handbooks, distribution of Relative Accommodation brochure, GP checks and review of the AHLO services were fully or partially implemented.

Table 2. Hunter New England Implementation Assessment

Strategy	Fully or Partially Implemented
Cultural Respect Education	100%
Enhance physical environment	100%
Shuttle bus transfers from train station	100%
Two escorts covered by IPTAAS	92%
Review space for family gatherings	92%
Collaborative relationships	83%
AHLO network forum	83%
“Speak Up” posters	83%
Retrain staff on Identification Guidelines	75%
Recruit Aboriginal people	75%
Potential for further outreach services	75%
AHLOs well informed	67%
Standardised core roles AHLOs	58%
Accountabilities in job descriptions	58%
Aboriginal Impact statements	58%
Improve discharge planning process	50%
Cultural issues in education	50%
Review transfer of care processes	42%
Electronic discharge summaries	42%
Patient handbooks	33%
Distribute Relative Accommodation brochure	25%
GP checked, updated and recorded	8%
Review AHLO services extend hours and both genders	0%

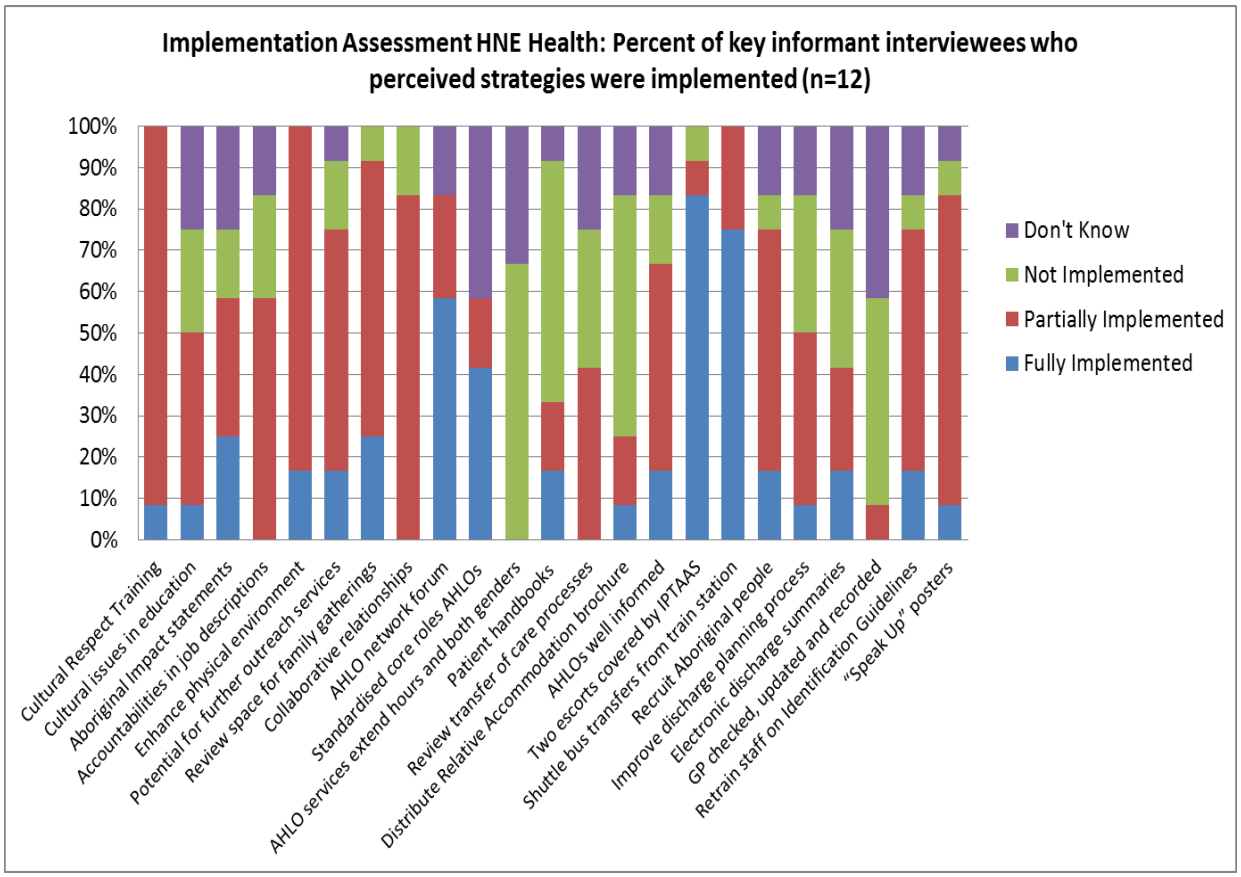

Figure 5. Assessment of Whether Solutions were Fully Implemented (HNE)

Is there a difference in the Aboriginal patient and family experience?

Northern NSW Aboriginal Family Stories

The family interviews were quite positive with most families being well supported by the AHLO and feeling comfortable whilst in the hospital at Lismore Base. One family were not offered any support. The major theme regarding any negative experience was the difficulty in obtaining transport home from Lismore to Casino. The issue of transport was raised in the project but no clear strategies were put in place to address this, therefore the issue still exists. A summary of the family stories for Northern NSW are in Appendix 6. Table 3 below provides an analysis of key changes noted before and after implementation of the project strategies in Northern NSW.

Table 3. Summary of the Impact of Changes Post Project Implementation (Northern NSW)

Feedback Pre Implementation Stage	Feedback Evaluation Stage	Change
"Staff at Lismore Base Hospital didn't tell me there was an ALO and I didn't know how to contact them either." "There was no Aboriginal worker at emergency to explain what was happening. Aboriginal worker needs to come to see me, come around at least once a day, cause I was alone with no family to support me" "Parents wanted to leave Lismore Base with baby because they weren't being treated right, no support…"	From the family interviews there were no issues raised whilst in hospital regarding the level of support given by staff within the emergency department and children services. All families had a positive experience.	Cultural Awareness training was modified from one full day to a number of 40mins sessions to enable the ward staff to attend. *"We done a 40 min one with staff over a month. We've seen 50 workers. It was good. We reduced it to the time factors. We've done a big one in Lismore for the managers. Looking at reducing it." – Aboriginal staff member.* Communication between staff improved following a new approach to training. *"Yes a bit more aware. I get that feedback from the workers…We communicate much better now. I think the awareness has more come to the front.""…you rarely hear now 'don't go up there' "* - Aboriginal staff
"We stayed in (receiving hospital) for a week, and when Tommy was released, I had to get my own way home"	3 of 5 families had difficulties in getting transport home. One family reported their only negative experience was feeling stranded when discharged. They also said there was not enough communication about discharge. *"Transport home is still the biggest problem. There's no buses. It's the same if you want to go to Tabulum this afternoon how do you get there?…Community don't have a lot of transport, and it's not pay day and the petrol's empty…They come in by an ambulance and usually it's just one sometimes its dad. Doesn't matter who comes. When you come in by ambulance to Lismore and then need to get home."* Staff Interview	Only half of key informants mentioned that any discharge planning improvements were implemented. Therefore the experience for families does not appear to have improved with transport and discharge planning remaining the major issue for families travelling home to the Casino area.

Hunter New England Family Stories

Overall, the stories of families travelling away from home for a higher level of care in the Hunter New England region were positive when there was good support from the AHLO and good information regarding what to expect during the stay and at discharge (Summary of stories in Appendix 7). Julie and James were well informed, well supported by the AHLO and involved in the discharge plan. Julie had no suggestion to improve the journey from the perspective of travelling away from home for care. Where there was limited support such as in the case of Jackie and Jane, the experience was stressful. Jane had a positive experience in terms of feeling safe with the care provided, but was not well supported with information, did not see an AHLO and was not asked whether she was Aboriginal. Jackie's experience was especially stressful, and she suggested that the service could improve by offering contact with the AHLO, staff to book travel home for parents, and providing a handbook of what is available (accommodation, meals, teller machines) and having an awareness that it is not easy to travel to hospital with a child when there are children at home to look after.

Table 4. Summary of the Impact of Changes Post Project Implementation (HNE)

Pre Implementation Stage	Evaluation Stage	Change
"I think some admission staff assume that white faces are not Aboriginal people and don't ask the question" – Aboriginal Health Worker Documentation of Aboriginality in hospitals is poor	One of the four parents interviewed was not sure if the staff new that she was Aboriginal. She was not asked.	Identification of Aboriginality still does not seem to be routine practice.

Pre Implementation Stage	Evaluation Stage	Change
"Family stayed at the hospital till 9.00pm hanging out in the play-room. We tried to stay longer but they didn't like us staying late. We got the impression we weren't wanted. You can pick it up with those fellas over there".	None of the families interviewed discussed the environment or commented on being made to feel uncomfortable by staff. *"There was two car loads of us staying at Ronald McDonald House. We went out in the day to my sister's house because there was so many of us…I slept every night with her in the ICU…we was made to feel welcome."* Family Interview	There seems to be a change in that Aboriginal families felt comfortable. *"We had lots of contact with [AHLO]. We were given parking vouchers, meals were organised, and staying at Ronald McDonald House…the ICU called [AHLO], and he arranged everything" "…more families are starting to speak up"* Aboriginal Health Worker
"Some Aboriginal Families are not aware of the accommodation services that are available to them" Aboriginal Health Worker *"Aboriginal staff are not available at the hospital to assist families after hours and on weekends"* – Aboriginal Health Worker *"I only call the ALO if the family request it"* – Nurse	Two of the four families interviewed had contact with the AHLO. Only one of the four families interviewed was assisted with accommodation. *"No. They don't have Ronald McDonald House there… because I had no idea, I'd never been…Upstairs there was cafeterias but I had no idea"*	Support from AHLO's was not made available to all families. The implementation assessment showed that review of AHLO availability after hours and on weekends was not implemented.
	Jackie was not supported well in her journey. She did not have any contact with the AHLO. The discharge process was not well organised and left her isolated and vulnerable. The handbook was not made available to the family and accommodation options were not offered. "*But they never brought me any food either. They didn't tell me - because I had no idea, I'd never been to John Hunter before - that there was three levels. Upstairs there was cafeterias but*	Although handbooks about the Children's Hospital were implemented, they are not routinely provided to families travelling for care.

Pre Implementation Stage	Evaluation Stage	Change
Discharge planning does not routinely involve families.	*I had no idea*." Family Interview *"When we first got there we couldn't find where he was. You had to go in the doors and then up lifts and out and chuck a right. Okay, we're getting lost."* On discharge Jackie needed to find her own way home. She did not have any money. She did not know where to go to catch the train home, or if she would be able to do so. A nurse on the ward booked a car to take her and her daughter to the train station. She was concerned that she would not be able to get a seat on the train, but this was not a problem and family arrived home safely. Katie needed a follow up check several months later. This was arranged to occur near her home at the Aboriginal Medical Service with the outreach clinic.	Discharge planning for travelling home still does not routinely involve families. *"I don't think we engage families very well in discharge planning at all." – Staff Interview* Positive change was noted by a manager in follow up care: *"I think we have clinicians who are continuing to make real shifts in the way they work with Aboriginal families…They do it in one to one interaction, they do it in just being more cognisant of trying to schedule appointments… They also do it in ways of trying to be more flexible in outreach clinics."*

Do Aboriginal staff detect a difference in the workplace?

Northern NSW

Aboriginal staff detected a strong difference in paediatric services in Lismore: *"…the only big change [in the hospital] is in the children's ward… I get a lot of support from that ward than any other ward. That's where the problem is when the children come in, the young mums are scared – they don't open up -frightened they'll say something…It is much better in the children's ward now. As soon as [nurse unit manager] rings or pages me I'm there and dealing with the problem or sorting things out. She says 'I don't know what we'd do without you'.*

Discharging them from hospital and that, before they had to find their own way home. Now it's totally different. They call me a lot more. I go to discharge meetings and phone around and get them home and all that." Aboriginal staff

There were positive themes from the stakeholder interviews regarding the cultural awareness training and the physical environment solutions. All of the Aboriginal staff detected a major difference especially with the hospital physical environments: *"Everybody's really happy with it. To go ahead and do something like that it's really something. People come in and see that. The Community are happy with it."* – Aboriginal staff.

Hunter New England

In HNE Aboriginal staff participating in the key stakeholder interviews detected a difference in the workplace with 40% detecting a major difference and 60% some difference (Figure 7). The key areas of change detected by Aboriginal staff were in attitudes and the physical environment: *"…there has been a change for the better…a change in staff attitude…an acceptance…staff are treading lightly with the culture and learning to know how to ask questions"*- Aboriginal Staff

Visibility of Aboriginal artwork and flags was important. "*They* [the children] *know the colours and feel comfortable then"* Aboriginal Health Worker. Visibility of Aboriginal staff and family was also important. It was noted that the 'Welcome to JHH' video that is run in various waiting rooms is helpful. The photos of Aboriginal people on the walls in the main entrance to JHH were also reassuring for staff and families. In the family interviews, one mother of a child who travelled from Moree was *"surprised and excited"* when she noticed a photo of her relative in the foyer of the hospital. She thought that it was *"really amazing that such a big place would have photos of the family".*

"I don't hear as many bad stories" – Aboriginal Staff

Moree Maternity Painting by Kathleen Green

Middle Camp by Marg Adams

Camps and Fauna around Mehi

Do non Aboriginal staff detect a difference in the workplace?

Northern NSW

Around 74% of non-Aboriginal staff interviewed detected a difference (Figure 6). *"The Waiting Room improved out of site…"* – Non Aboriginal staff member

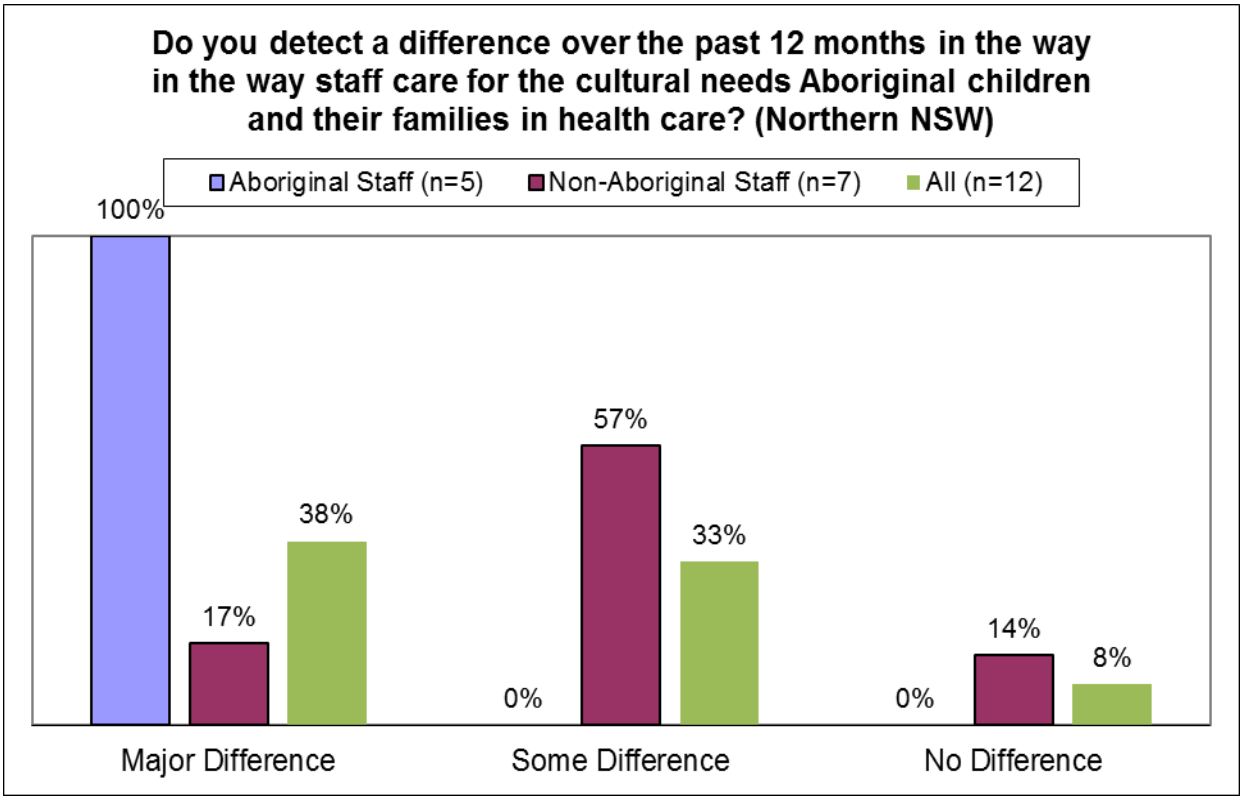

Figure 6. Percentage of Staff Interviewed Who Detected A Difference (Northern NSW)

Hunter New England

All non-Aboriginal staff interviewed in HNE detected some difference in the workplace (Figure 7). The "*Didja Know: Aboriginal Cultural Communication"* booklet that supported education and provided practical information was viewed very well. *"Didja Know was very good"*.

The organisation wide focus was seen as slowly creating a shift in attitudes of staff and how they interact with the Aboriginal community. "*People told us what they thought and why they didn't like coming into hospital. Why they thought that the hospital was for white people. They were coming in to something very foreign. We just assumed that Aboriginal people wanted to be together but we didn't know that some people did not want to be in the same room. Understanding that makes a huge difference." - Manager*

Interviewer: *"On a scale of 1 to 10, has the project been useful?"* Manager: *"I think it is an 8."*

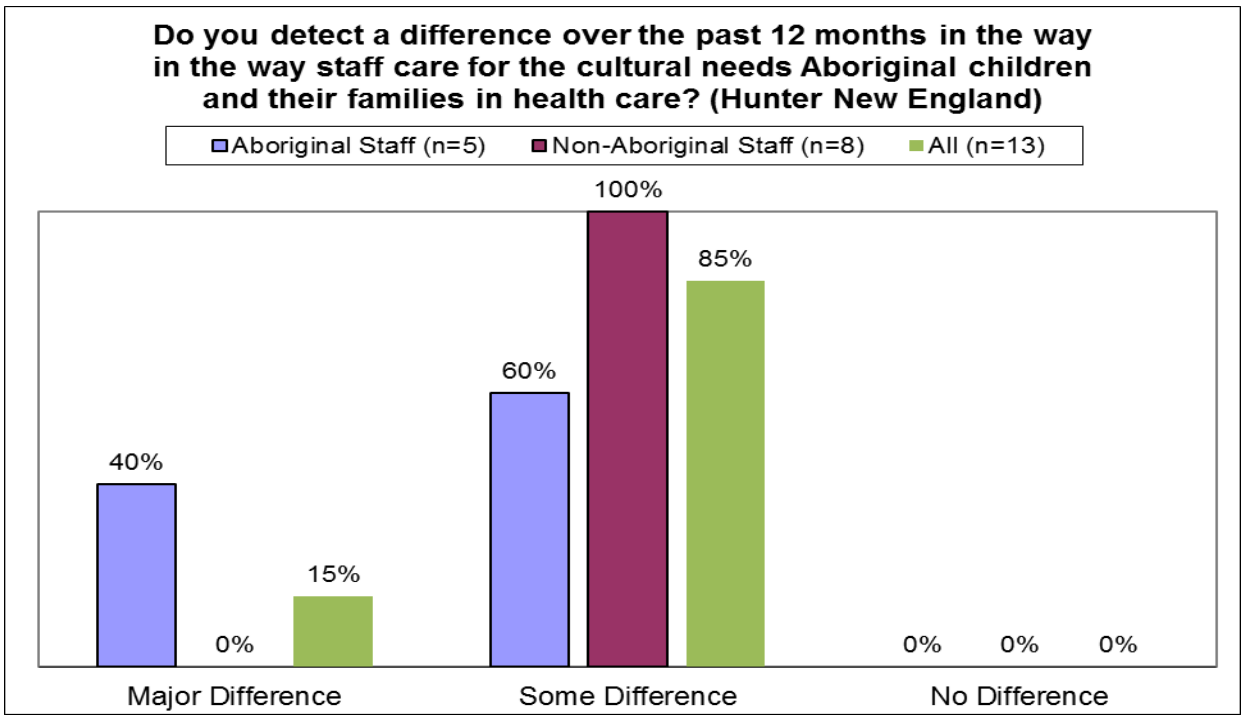

Figure 7. Percentage of Staff Interviewed Who Detected A Difference (HNE)

Critical Success Factors

If a difference in the workplace is detected, what were the critical success factors that brought about this change?

Northern NSW

Leadership

Initially there was Executive level leadership of the project, but with the restructure of NSW Health services, sponsorship of changes became unclear. The new model of Cultural Awareness training, Collaborative meetings and updating Aboriginal service directories were examples of effective strategies that have not been sustained or spread across services. Inter-service Collaborative meetings were started but ceased a few months after the initial project *"I tried to get people together but I gave up after a while."* Manager Interview. Establishing groups such as this required a lot of time and energy *"I think the answer is they needed someone to drive it…" – Northern NSW staff.*

Staff Involvement and Commitment

Staff reported that changes in Northern NSW were strongly supported by the frontline staff who were committed to improving the journey of Aboriginal children and families: *"I just found everyone supportive from day one. They were very supportive, people were keen they wanted it to work."* – Aboriginal staff member

Role of the Aboriginal Hospital Liaison Officer

There was very strong support in both Casino and Lismore for the role of the Aboriginal Hospital Liaison Officer (AHLO). The model in Casino was reported as very effective by all staff. *"The ALO is exceptionally good…before that we had nothing to bridge the gap…helps the hospital to work with the community".*

Cultural Awareness Training that Meets the Needs of Clinical Staff

The AHLO role in Casino has created strong relationships with the staff through the facilitation of cultural awareness training and being accessible. This has led to training that met the needs of the staff and a greater awareness of services.

"We had a problem with cultural awareness training - it always the whole day and was a lot of history but nurses wanted to know how to treat people properly, getting better cultural awareness and communication. We devised a series three 20 minute sessions where we had an overlap between shifts. I think that worked really well with people that they knew. Was a small environment and people felt comfortable to ask questions. With a big group you just don't have that. But this died out after the project. Awareness of services available was one of the best things." - Staff Quotes from Casino

Aboriginal Community Speak Up More

It was also suggested that the Aboriginal community is more likely to seek answers about their health care. *"We [Aboriginal people] are not as backward...we are upfront now and want to know what is happening."*

Hunter New England

Leadership of Cultural Change

It was generally acknowledged that leadership from the Northern Child Health Network and the Executive Leadership Team provided the platform for cultural change. The staff interviewed generally felt confident to implement a change when they were supported, "*all the way to the top"* and when the "*Organisation takes ownership of something so important".*

The leadership has led to systemic change in HNE including cultural competency built into position descriptions, the development of collaborative groups and extension of the use of Aboriginal impact statements into policy compliance procedures. Aboriginal issues and cultural issues are now discussed at Board level of Ronald McDonald House. *"Whatever we are doing now we consider Aboriginal issues."* – Staff Interview.

Organisation Wide Approach

Cultural change was perceived by two managers as resulting from a combination of strategies across the organisation:

> "*The other thing that happened at the same time was the Excellence Program and I think the respect that everyone is treated with - I think that that really helps as well…I*

round on the patients every Friday and ask how have the staff been. People say when I go to other places they don't check on me like they do here. Hourly rounding things like that. I don't get the complaints I used to. I don't get many complaints now. A lot of our patients are Aboriginal and I don't hear that racist stuff any more…Times have changed, a generational change. The two programs have worked well to develop mutual respect…I don't get many complaints now like I used to. A lot of our patients are Aboriginal...I used to hear that racist stuff I don't hear it anymore. Two programs have contributed to the change. Excellence came a few months after the Aboriginal Collaborative and I think brought more respect…" – Manager.

"…we do have a whole load of new services that we didn't have say three or four years ago. We've got the Building Strong Foundation services and the New Directions services. We have a CNC who works in Aboriginal Child Health. So her job is just to work with those seven or eight programs across the region. So in a sense, as an organisation, we're in a different place than we were five or six years ago because we have these services that didn't used to exist. So it forces us, forces managers to be really looking at how we, working with Aboriginal families, how we engage and deliver services to Aboriginal families." - Manager

Cultural Education and Communication

Education and attitudinal shifts were seen as fundamental to changes being implemented and sustained. This was achieved through a range of strategies but Cultural Respect Education underpinned much of the change in HNE. Most managers and senior clinicians from the Children, Young People and Families Clinical Network were made a priority to attend Cultural Respect Education as a result of the project. Attitudinal change was reported following the training *"Lots of people involved with family health have done the cultural respect training – they come back and they are very affected by it."*

Education, training and support enabled managers to think and talk about how they deliver services to Aboriginal children and families. "*…it opened up the space to be having those sorts of conversations with managers. Just thinking about what does it mean for a child that comes from Moree to Tamworth or for a child that goes from Tamworth to John Hunter Children's Hospital'.*

However, outside of the managerial and senior clinicians, not many of the staff at John Hunter Children's Hospital have attended Cultural Respect Education.

Role of Aboriginal Hospital Liaison Officer

The role of the AHLO was important in the journey of Aboriginal children and their family when travelling for care. The two Aboriginal families who had a stressful journey did not have contact with an AHLO, while those who did receive this support were very positive about the role. The role was also seen as important in preparing families to travel away from home: *"What we were going to do here is have information about what was available in Newcastle*

before people travelled. It was happening but not happening now…But because we don't have an ALO I don't think it is happening any more."- Rural staff interview

The AHLO is '*the key"* and "*invaluable to learn from…how to approach families". "After hours, it is still an issue. Staff can only do what they can do..."*- Staff member. The AHLO Forum implemented from the project was seen as important for information sharing and building relationships about other areas in the LHD.

Collaboration

The Collaborative Groups between Aboriginal staff and managers established at the three project sites have led many of the local changes. *"When we have the whole Aboriginal Collaborative together it's a really nice group. We work well together. The Collaborative seems to be the thing that's pulled everyone together in a big meeting place. Around the Aboriginal journey that's where it all gets directed from." – Manager*

According to one Aboriginal manager "Collaboration and communication is the key" and "Barriers between staff have broken down" with "A common space for people to meet on equal ground". The Collaborative Groups have now spread to other sites across the HNE Local Health District. The groups all function differently as they have been established to meet the needs of the local communities.

Staff reported that the difficulty in establishing and maintaining these groups should not be underestimated. For example, the Collaborative in Newcastle started up but had difficulty engaging Aboriginal staff to regularly attend. A key learning reported by stakeholders was that it is critical to have a clear process for non-Aboriginal staff to consult and engage with the Aboriginal community in developing and implementing changes. *"We are building stronger collaborative relationships but it needs a lot of work to maintain it."* - Manager
Also that Collaborative Groups *"Gives wins that we can't get in other ways but they are hard work"* – Aboriginal Manager

Resources to Support Implementation

The passion, commitment and drive of the Project Officers was seen as critical in supporting the implementation of change. In HNE, two project officers, one Aboriginal and one non-Aboriginal, were appointed to support implementation over an additional 12 month period compared to NNSW. Strong support to establish the Collaborative Groups at each project site contributed to these groups being sustained and spread across HNE which did not occur in NNSW where there was not a dedicated project implementation officer. As stated by a manager *"for me, really big achievements were things like having the two project officers...the other thing, which is a fairly simple thing but makes quite a significant difference for Aboriginal people, by having [project officers] in the position they were able to negotiate something with IPPTAS so that Aboriginal patients could legitimately have a second carer travel with them. I think that's such a significant thing…"*

Conclusion

Overall, most staff in Northern NSW perceived that the project was either effective or very effective in meeting the objectives. “Provide cultural knowledge to children’s health planning” was rated the least effective in Northern NSW but rated highly effective in HNE. The objective of “identifying involvement of Aboriginal families in discharge planning” was rated as least effective in HNE but rated more highly in Northern NSW.

Most strategies were partly implemented and most staff detected a difference in care provided to Aboriginal people. Cultural Respect Education in HNE and Cultural Awareness training in Northern NSW along with enhancements to the physical environment were rated the highest as strategies that were either fully or partially implemented. A higher percentage of Aboriginal staff detected a change compared to non-Aboriginal staff in both health services.

Positive themes across both LHD’s included a cultural shift in children’s services and the families reported that they felt they received good care by competent staff. The common theme across both services was that families who had a lot of contact with AHLO’s had a much more positive experience than those that did not have that contact. The implementation assessment also showed that the recommendation to extend AHLO services was not implemented.

The main finding for both LHD’s where there was not a positive improvement resulting from the project was in discharge planning processes, including the organisation of transport. Even though 77% of staff interviewed in NNSW reported that improved discharge planning had been implemented, the difficulty of obtaining transport home is the common theme for families. The need for good transport is critical for rural families and lack of transport impedes access to health care[7].

The Cultural Awareness (NNSW) and Cultural Respect (HNE) training were found to be the main changes that led to attitudinal shifts and in both areas resulting in action being taken to improve the experience of Aboriginal families travelling for care. Coffin et al[8] (2008) explain that there are various levels of cultural understanding required to translate information into action. Cultural awareness is a basic understanding of a relevant cultural issue that does not necessarily lead to action. Cultural safety is the next level achieved when people have a deeper level of understanding leading to more appropriate action being taken. In both Northern NSW and HNE the training resulted in clear actions taken to improve the cultural safety of Aboriginal families. This appeared stronger at the ward level in Northern NSW where flexible cultural awareness training had been delivered to clinical staff by a highly respected AHLO. This AHLO had also worked with the Aboriginal community to support people to speak up more. In HNE the cultural changes were more systemic and actions more visible at Executive and senior managerial levels where Cultural Respect Education had been targeted.

In HNE, where the approach to cultural change was organisation wide with strong Executive leadership, there was found to be a greater level of sustainability and spread of the improvements. Strategies for change appeared to be more embedded within planning for children's services. In NNSW the visibility of leadership lessened over time and the changes were led by frontline clinicians. The commitment of the frontline managers and the Aboriginal staff was critical in leading the changes in Northern NSW.

The other factors found to be critical for change were involvement of Aboriginal Hospital Liaison Officers with families, collaboration, communication processes and resources to support implementation. The Collaborative partnerships were important but reported as being difficult and hard work. The benefits of collaboration and partnership is supported by Stamp et al[9] (2008) who found that an inter-cultural partnership model established to tackle the issue of Aboriginal mothers' and babies' health took commitment and time, but resulted in clear benefits and improved cultural safety.

Recommendations

The following recommendations are made based on the findings of this evaluation.

8. Senior executive leadership develop and support a process to embed the strategies that were implemented and found to be effective but were not sustained and assess the continued relevance of strategies that have yet to be fully implemented from the project.
9. Consideration is given to implementing more widely the flexible approach taken in Casino for cultural awareness training delivered by a respected Aboriginal Hospital Liaison Officer to ward based clinicians. This model was reported as having a very positive impact by both the local Aboriginal staff and the clinicians.
10. In order to improve communication, build relationships and build cultural competence, it is recommended that Aboriginal Hospital Liaison Officers are trained to participate in cultural respect or cultural awareness training at local sites.
11. It is recommended that the strategy from the project to review and extend AHLO hours and gender mix be reconsidered as support from an AHLO was a critical factor for Aboriginal families to have a positive experience when travelling for a higher level of care.
12. Improve the dissemination of the 'Patient Information Guide' to families travelling for care to John Hunter Children's Hospital. Aboriginal families in HNE requested that a handbook is made available to understand what resources are available, including accommodation and AHLO contact details. Although this handbook is on the Kaleidoscope website, it is difficult to find and not reliably disseminated to families. The Directory of Services in NNSW requires a process to keep it updated.
13. As transport home and involvement in discharge planning was one of the main issues for Aboriginal families, it is recommended that clearer transport options are given to families well in advance of discharge. The involvement of the AHLO in planning for the travel home is pivotal to the experience of the family.

14. A positive outcome from the project was the enhancement of physical environment of the health services. Aboriginal families acknowledged that artworks, flying the flags and seeing photos of family and friends from their community contributed to the level of comfort and welcome they felt when accessing the health services. It is recommended that the health services continue to support the improvement of the physical surroundings throughout the health services to acknowledge the traditional owners of the land.

References

1. Close The Gap: Solutions To The Indigenous Health Crisis Facing Australia: A Policy Briefing Paper From The National Aboriginal Community Controlled Health Organisation And Oxfam Australia April 2007

2. ABS Data 2005. Available at: http://www1.hnehealth.nsw.gov.au/hneph/HHNE/dem2/dem2_ATSI_Cluster.htm

3. Two Ways Together Regional Report North Coast Region, 2006

4. Hunter New England Area Health Service Aboriginal Health Plan 2007-2011

5. Two Ways Together Regional Report New England/North-West Region, 2006

7. Dywer, J., Kelly, J., Willis, E., Glover, J., Mackean, T., Pekarsky, B. & Battersby, M. 2011, *Managing Two Worlds Together: City Hospital Care for Country Aboriginal People – Project Report,* The Lowtja Institute, Melbourne.

8. Coffin J, Drysdale M, Hermeston W, Sherwood J & Edwards T. *Ways forward in Indigenous health* (Ch10) In: Liaw & Kilpatrick (Eds.). *A Textbook of Australian Rural Health.* Canberra: Australian Rural Health Education Network, 2008.

9. Stamp GE, Champion S, Anderson G, Warren B, Stuart-Butler D, Doolan J, Boles C, Callaghan L, Foale A, Muyambi C. Aboriginal maternal and infant care workers: partners in caring for Aboriginal mothers and babies. *Rural and Remote Health* 8 (online), 2008: 883. Available from: http://www.rrh.org.au/publishedarticles/article_print_883.pdf (accessed 20 June 2012)

Appendices

Appendix 1 Summary of Key Issues Identified in the Project

1. Cultural Safety: Cultural Competence:
    - Expressed a lack of clarity in understanding how best to meet the individual and cultural needs of Aboriginal families when their child is admitted to hospital.
    - The physical environment of health services feels foreign and unfamiliar to Aboriginal people.
    - Lack of space in hospitals for large families to be present with child.
2. Cultural Safety: Collaboration:
    - Low numbers of Aboriginal workers in frontline positions diminish capacity to provide culturally appropriate child health services.
    - Limited collaboration between Aboriginal Health workers.
    - Limited involvement of Aboriginal Health staff to develop culturally appropriate health services for children.
    - Limited collaboration, few outreach services and referral pathways increases the need for travel.
3. Support for Travel:
    - Transport availability and cost are regularly identified as significant barriers to accessing government services and impacting on health outcomes.
    - Limited information regarding availability of transport and accommodation options for families.
    - AHLO's are not routinely informed of patient transfers to other facilities to provide follow up support.
    - Difficult IPTAAS process.
3. Discharge information and follow-up care could be improved
    - Hospital staff lack knowledge of available health services in rural communities for follow-up care
    - No defined process to inform Aboriginal support services that patients have been admitted or transferred to another hospital so they can provide follow-up contact.
    - Children have been discharged without a plan regarding how the family will return home, and many Aboriginal families do not have access to private transport.
    - Aboriginal health care workers and providers are not routinely included or informed about discharge plans
5. Data Collection
    - Documentation of Aboriginality in health systems is not reliable.

Appendix 2 Project Recommended Strategies: Implementation Assessment Tool

	Strategy	Full	Partial	Not Implemented
Cultural competence of services	Cultural Respect training in (HNE Health)			
	Accountabilities for cultural competence in job descriptions (HNE Health)			
	Inclusion of cultural issues in education programs			
	Extend use of Aboriginal Impact statements in all child and paediatric services			
	"Didja know: Aboriginal Cultural Communication" staff handbook for HNE Health			
Hospital physical environments	Enhance hospital physical environments with culturally appropriate Aboriginal signage and artworks, including posters, use of Aboriginal colours in signage, display of Aboriginal flags and welcome signs on hospital entry in the language of the traditional owners of the land for each site.			
	Review available space for family gatherings within and outside hospitals.			
Inter-service collaboration	Build stronger collaborative relationships and communication protocols between paediatric health services, Aboriginal Health Workers and key stakeholders including Aboriginal Medical Services.			
	Establish an Aboriginal Hospital Liaison Officer (AHLO) network forum for each AHS.			
	Support the development of standardised core roles for AHLOs			
	Explore ways to ensure Aboriginal hospital liaison services are available extended hours and covering both genders.			
	HNE Health: Potential for further outreach around staff education and outreach clinics to communities if further community consultation also identifies outreach clinics as a need.			
Access to Support when Travelling away from Family and Land	Build on existing patient handbooks across the Northern Child Network to provide easily accessible information (available on the intranet/internet) on children's services that includes culturally appropriate support information such as:			
	- transport and accommodation			
	- roles and duties of Aboriginal Health workers and Aboriginal Medical Services			
	- IPTAAS information, forms and assistance in completing forms i.e. relevant Social Work contact			
	Review HNE Health transfer of care processes to be more culturally appropriate including a package of information to be given to family as part of the transfer of care process			

	Distribute the HNE Health Rankin Park campus "Relative Accommodation" brochure to referring facilities (HNE Health)			
	AHLO's are well informed of admissions and transfers of Aboriginal children by a variety of means including an electronic report generated in hospital information systems.			
	HNE Health to trial, until the end of the financial year 2009, IPTAAS eligible Aboriginal children being transferred to a higher level of care also being eligible to have two escorts covered by IPTAAS without the need for a medical doctor to approve the extra escort providing IPTAAS is made aware of the need prior to child's transfer. (HNE Health)			
	Explore options for the HNE Rankin Park campus shuttle bus to pick up and drop off people at the Broadmeadow train station to meet the Tamworth/Moree train (two trips/day).			
	Where appropriate designate and recruit Aboriginal people to front line clinical areas.			
	Promote student work placements, trainees and cadetships to Aboriginal people			
Discharge Planning	Improve discharge planning process to be culturally appropriate:			
	- encourage staff to ensure Aboriginal families are invited to become more involved in the discharge planning process;			
	- ensure all relevant service providers have timely access to discharge information to support ongoing care;			
	- plan on how families will return home including consideration of access to available transport.			
	Electronic discharge summaries are available in the Clinical Applications Portal (CAP) when patients are transferred back to the referring hospital (in HNE Health).			
	The child's GP is checked, updated and recorded into iPM on admission as normal procedure.			
Data Collection	Retrain admission staff in compliance with NSW Health guidelines "Better Practice Guidelines to Improve the Level of Aboriginal and Torres Strait Islander Identification in the NSW Public Health System"			
	Display "Speak Up" posters at admission points (Admission Office, ED & Wards) that encourage Aboriginal people to identify their Aboriginality.			

Appendix 3 Questions for Aboriginal Family Interviews

1. Can you please tell me, very briefly, why your child was admitted to [insert name of relevant hospital here] and in what month and year did this occur?
2. Can you please tell me about the things that happened to you and your child from the time you left home to go to the hospital until you returned home again?
3. Can you please tell me about the parts of your experience that you found the best and how they made you feel both physically and emotionally?
4. Can you please tell me about the parts of your experience that you found the worst and how they made you feel both physically and emotionally?
5. From your experience, what needs to happen to better support an Aboriginal family when their child is admitted to a hospital outside of their local community?
6. From your experience, what needs to happen to better support an Aboriginal family when their child is admitted to a hospital outside of their local community, specifically in relation to travel, accommodation and social support arrangements?
7. Do you have anything else you would like to say?

Appendix 4 Information Sheet for Aboriginal Families

You have been invited to help us understand your experience when you needed to travel away from your community for your child to go to hospital outside of your local area.

As part of the Journey of Aboriginal children and their families throughout the Northern Child Health Network project, we would like to invite you to tell your story about your experience in travelling away for your child to receive health care.

Before you share your story and experience, it is important to understand why we would like to speak with you and what it will involve.

Please take the time to read this Information Sheet and talk to us if you have any questions.

1. Why have I been invited to share my story?

You have been invited to share your story because you have recently travelled away from home and community for your child to receive health care.

2. What will sharing my story involve?

If you want to share your story, we will arrange a time that suits you to meet with you in person or talk on the phone, this will take no longer than one hour.

We will not ask you questions about your child's medical treatment or results – we want to know about you and your child's experience.

We would like to hear about:

- Why your child was admitted to hospital
- What happened from the time you left home to go to the hospital until you returned home again
- How the experience made you feel
- The best parts of your experience
- What would have made it better

If you are happy to share your story, we will ask you to sign a form when we meet which gives your permission for us to collect your story.

With your permission, the interview will be recorded on audio tape and then written down to make sure it is correct. We are not able to guarantee privacy of your identity with the use of voice recordings. You can ask for the tape to be stopped and sections of it edited or erased at any time during the interview. We will destroy the tapes later, or if you prefer, the tape may be returned to you.

You will be able to look at your story once it is written to change anything that is not correct.

Your story will be kept safely and be used only once your personal identifying details have been removed.

3. What if I don't want to share my story, or if I want to withdraw it later?

<u>The choice is yours!</u>

If you do not want to share your story you do not have to take part. If you do not want to share your story that is ok, your decision will be respected and will not change anything about the care you or your child receives.

If you decide to tell your story, you may also stop this at any time and you don't need to give a reason, just tell us or fill in the attached form.

4. Who will be there when I share my story?

A member of the project team will meet with you to talk about your experience. An Aboriginal Health Worker may also attend with your permission.

If you wish, you are welcome to have a family member or friend with you when you share your story with us.

5. Will it cost me anything to share my story, or will I be paid for it?

It will not cost you anything to participate and you will not be paid to share your story.

6. How will my identity be protected?

We will change any details which are personal to you for example your name and address.

Sometimes under special conditions we are required by law to report if you were a victim of a criminal act while in our care.

While this is rare, it is our responsibility to make sure all patients are safe whilst in our care.

7. What happens with my story?

Your story will be used to look at how well we are doing to improve the experience of health care for Aboriginal families.

Some of your story may be told to help other health care workers improve their services. If we tell your story, we will not use your name or any personal information.

8. Who should I contact if I have problems after the interview?

Dallas Waters (Maclean) Project Officer PO Box 93, Maclean Community Health NSW 2463, Phone: 66400123
Email: Dallas.waters@ncahs.health.nsw.gov.au
Leanne Fitzgerald (Inverell) Project Officer PO Box 701 Inverell Community Health NSW 2360 Phone: 67219600
Email: Leanne.Fitzgerald@hnehealth.nsw.gov.au

If you feel that you would like to speak to a counsellor for emotional support following the interview, please contact: Sally Abrahams: (02) 6640 0123 Social Worker, Maclean Community Health ***Complaints about this research***

This research has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Health, (Reference 10/12/15/4.08) and by the Aboriginal Health and Medical Research Council (AH&MRC) Ethics Committee (Reference 765/10)

Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to either:

Dr Nicole Gerrand, Manager Research Ethics and Governance Hunter New England Human Research Ethics Committee, Hunter New England Health, Locked Bag 1, New Lambton NSW 2305, telephone (02) 49214950, email:

Hnehrec@hnehealth.nsw.gov.au.

You may also contact Mr Bob Davidson, Executive Officer Aboriginal Health and Medical Research Council, Human Research Ethics Committee. Level 3, 66 Wentworth Ave, Surry Hills, 2010. Telephone (02) 92124777, email:

ethics@ahmrc.org.au

Appendix 5 Staff Interview Questionnaire

After introduction, ensure consent form signed before proceeding with the interview including agreement with taping.

Questions will be modified depending on who is being interviewed to allow open ended responses.

Are you an Aboriginal or Torres Strait Islander staff member: YES NO

1. The project aimed to gain insight to improve the journey of an Aboriginal child and their family after a decision is made to transfer the child's health care from a lower level of care in their local community, to a higher level of care outside their local community. Do you believe that this aim has been achieved?
   If yes, what have been the most valuable insights gained? If no, why not?
2. On a scale of 1 (very ineffective) to 5 (very effective), please rate how effective you think the project has been in achieving the following objectives? (Each participant in focus groups given the table below (Likert Scale) to complete)

Objectives of "The Journey of Aboriginal children and their families throughout the Northern Child Health Network"	1 - Very ineffective	2 - Ineffective	3 – Neither ineffective or effective	4 - Effective	5 - Very effective
Confirm what constitutes a culturally appropriate health service for Aboriginal children and their families					
Explore communication between hospital staff and Aboriginal children and their families					
Identify the level of involvement Aboriginal children and their families have in health care and discharge planning					
Identify what support and assistance is required for Aboriginal families when their child's health care is transferred to a service outside their local community, in particular travel, accommodation and social support arrangements					
Build on existing initiatives so that the best possible and culturally appropriate supports are accessible to Aboriginal families when their child's health care is transferred to a service outside their local community					
Provide cultural knowledge to children's health planning to ensure improved health experiences and outcomes for Aboriginal children					

3. Do you detect a difference over the past 12 months in the way staff care for the cultural needs Aboriginal children and their families in health care?
   YES, major difference YES, some difference NO, no difference
   i. If yes, what were the critical success factors that brought about this change?
4. What do you think has been successfully implemented and sustained? (Supply "Implementation Assessment" document & ask staff to assess)
5. What about those solutions that you think were NOT successfully implemented and sustained? Why do you think they were not implemented?
6. What do you think have been the most significant benefits that have occurred as a result of the project? Explore any real success stories that can be written up in the report. (Prompts – tangible, intangible)
7. What do you think are the key learnings for others who undertake similar types of projects?
8. Are there any further comments you would like to make?

Thank you for your time

Appendix 6 Aboriginal Family Stories (Northern NSW)

Box 1. Tom's Story (Northern NSW)

Tom and his child James presented to Casino Hospital after James was suffering from shortness of breath at home. It was decided to transfer James to Lismore Base Hospital and transport was offered to the family. Staff at Casino notified LBH that they were going to present there. Accommodation was offered to both Tom and his wife once they arrived there.

Tom's experience at LBH was very positive as James was there for 4 days until he responded well to the medication. Tom said staff on the children's ward included them in their discussion and were very informative about the treatment for James which made him feel good about.

Tom mentioned that he didn't know the position of AHLO existed at LBH as there was no visit from the AHLO while they were there, however he didn't think this was a negative aspect as the non-Aboriginal staff were very supportive and looked after them.

Toms overall experience was very positive and on discharge staff was only too happy to assist and made them aware of James's follow-up appointments. Tom suggested that there needs to be an advertisement or photo of the AHLO throughout the hospital so families can identify and be made aware of the position of the AHLO as Aboriginal families sometimes require cultural support that the AHLO can provide.

Box 2. Lisa's Story (Northern NSW)

Lisa and her child Emily presented to Casino Hospital when Emily broke her left leg. Emily at the time was 3 years old and was transferred to LBH in an Ambulance. Emily's length of time in LBH was 4 weeks. Lisa would stay during the week and then would swap with her husband on the weekends. The family would travel to Lismore every week from Casino to Lismore and were offered no travel assistance.

Lisa mentioned during their lengthy stay she didn't have the Aboriginal Hospital Liaison Officer visit to comfort, support them and felt this should have happened.

Lisa mentioned that the nursing staff within the paediatric ward at LBH was nice and supportive and included them with what was happening with Emily.

A negative aspect of Lisa's hospital stay was when DOCS were notified and visited the family in relation to Emily's injury, however there was another family that presented to LBH with the same injury as Emily and there was no DOCS notification or follow-up with them. This made Lisa upset as to why her daughter and family were subjected to this and not the other family.

Lisa also acknowledged the artworks, posters displayed at Casino and Lismore and said she identified with them as she was related to the artists and that made her feel welcome and comfortable.

On discharge Lisa said she was comfortable with the stay at LBH considering the length of stay but in relation to going home family were responsible for their own transport. Lisa also mentioned that it would have been good if the AHLO visited them. Lisa and her husband had their own transport.

Box 3. Jan's Story (Northern NSW)

Jan and her child David journey from Casino to Lismore Base Hospital was good. Jan was satisfied with the transfer and happy with the staff reception and care at LBH. Whilst in hospital at LBH Jan felt supported from the staff and AHLO and her overall experience was good.

Jan's only negative experience was she felt stranded when discharged from LBH as she had to organise her own transport home. Jan also mentioned there was a lack of communication in relation to discharge. Overall Jan said that if there was improvement with transport and communication when released from hospital it would make her journey and experience much more positive.

Box 4. Nora's Story (Northern NSW)

Nora and her child David are regular visitors to Casino Hospital as David suffers from a disability. Nora is a single mother with other children and is frustrated with the lack of facilities at Casino Hospital for children and then being transferred to Lismore Base Hospital.

Nora expressed there was a lack of support with transport on weekends and after hours. She felt angry that as a single mother there was no consideration of her other children who had to go to Lismore at any time of the day and this gave her a lot of stress as the children became upset.

Nora said a good outcome was put in place when David is transferred to Lismore from Casino LBH staff notified Dr Tyrell who David has rapport with.

Nora recommended that staff need to be more aware of family circumstances when transferred outside their region to possibly prevent the transfer.

Nora mentioned that Travel is a big issue when it's after hours. Taxi vouchers should be offered and that she shouldn't have to ask for them all the time. On discharge Nora was happy with their stay in LBH however there were no offers of transport or assistance to get back home to Casino. Nora said she had to rely on other family members to come from Casino to get her and take her family back home.

Box 5. Camelia's Story (Northern NSW)

Cara and her son Tobin journey was very positive. Tom presents to Casino on a regular basis as he is Type 1 Diabetic. Cara mentioned the staff were pleasant and very informative about Tom's Type 1 diabetes and they felt their stay was more relaxing once everything was settled. Cara mentioned that the environment is friendly and the waiting room at Casino was very welcoming. Children's ward at LBH was amazing and suitable for her son and the reception they received had been fantastic.

Cara mentioned that there was family support offered by the staff while at LBH and this included the AHLO.

There was no assistance offered in relation to travel and accommodation as her husband required the only car for the other children. Meals were unbelievably priced and cost a fortune which was difficult being a low-income earner.

On discharge Cara was happy and positive with her overall experience from the staff, AHLO and the physical environment and was well supported during her stay at LBH however would like to see some improvement when her family and future families are required to travel back home to the Casino area.

Appendix 7 Aboriginal Family Stories (Hunter New England)

Box 6. Jane and Jerimiah's Story (HNE)

Jerimiah was flown to a tertiary referral hospital from a rural referral hospital as he was born seven weeks premature. Jane, his mother, was unable to fly with him as there were "too many nurses on the flight". When the baby arrived at the hospital, the staff of the Neonatal Intensive Care Unit (NICU) contacted her in the referring hospital to let her know his condition and to reassure her that her baby was OK.

Jane travelled the next day with her partner and his uncle. Her sister-in-law lent them money for travelling expenses. The staff at the referring hospital had advised them to find accommodation in Ronald McDonald House. When they arrived at the referral hospital they found it difficult to locate the NICU and got lost several times.

They were in the hospital for 12 days. Jane felt very safe in the NICU because she knew that the staff were very capable of caring for her baby and were very supportive. They were with her all the time and answered all of her questions.

She was not sure that they knew that she and her baby identified as Aboriginal. Jane says that she did not notice the Aboriginal colours or receive a quilt with Aboriginal artwork on it.

Jane felt quite lonely at times and this was her biggest concern. Her partner needed to travel home after a few days and she was left on her own. She felt scared and a bit emotional.

When Jerimiah was ready for discharge, there were no beds available in the referring hospital, so they stayed for an extra five days. Jane felt a little uneasy as she could not give Ronald McDonald House a definite discharge date. This caused her to nearly lose her room on a couple of occasions. On discharge Jane and Jerimiah were flown back to the referring hospital where they stayed in hospital for another three weeks.

Overall, Jane had a positive experience. She did not have any contact with the AHLO or any information about the referral hospital prior to going there. She felt safe with the staff but didn't know whether they knew that she was Aboriginal. Jane feels that a handbook to inform families of what they need to know when travelling would be beneficial. This could include accommodation, contact numbers, including the AHLO, the layout of the hospital, where to get meals and how to pay for parking.

Box 7. James's Story (HNE)

James's grandson was transferred by air ambulance from a rural referral hospital to a tertiary referral hospital with a throat abscess. James travelled with him.

James felt that the entire process was good. He felt included in all areas of his grandson's care. He found all the staff were professional and gave him all the information that he and his grandson needed.

James slept beside his grandson and utilised the units at the back of the hospital to shower and dress. He had contact with the AHLO and he feels that this is what made the situation easier. All queries and concerns he directed to the AHLO.

On discharge he travelled home with family who had travelled to visit them in hospital, stay a few days and take them home. They knew that they would have to find their own way home.

James's recommendations to improve the service include communicating well with the families and keeping them informed of what is going on at every step of the way and contact with the AHLO as soon as possible after they get to the Hospital. The roller beds in the children's ward could be more comfortable. This family's journey was very positive and well supported.

Box 8. Julie and Katie Story (HNE)

Julie took with her child Katie, aged 9 months, to a district hospital where she was admitted overnight. Her condition slowly worsened so the decision was made to transfer her to a tertiary referral hospital. Katie was treated for nine days in the Intensive Care Unit for bronchitis and lung collapse and then for seven days in the children's ward.

Julie was able to fly with Katie to the hospital while the rest of the family travelled the 500 kms by car. Julie had immediate contact with the AHLO who booked the family into Ronald McDonald House, provided parking vouchers and assistance with meals. Julie was surprised and excited when she noticed a photo of her relative in the foyer of the hospital. She thought that it was really amazing that such a big place would have photos of the family. Julie was made to feel welcome by all the staff and was very impressed with how the Intensive Care staff supported her and did not leave her on her own. "They made me feel happy that we were there".

The staff at Ronald McDonald house were equally supportive and helped all of her family while they were staying at there. Even though Julie was conscious that there was a large number of her family staying there, they were made to feel welcome.

Julie felt she was involved in Katie's discharge. The doctors wanted to see Katie again in a few days time. In consultation with Julie, it was decided that the family would stay near the hospital with Julie's sister for a few days, have the check with the doctor and then travel home.

Katie also need a check several months later. This was arranged to occur near her home at the Aboriginal Medical Service with the outreach clinic.

Julie said that is was good to have the help of the AHLO because the main issues for families were accommodation and looking after the other children while you are away from home.

Box 9. Jackie and Rebecca's Story (HNE)

Jackie presented to the Emergency Department of a rural referral hospital with Rebecca. Rebecca stated that her throat was sore and she had swallowed four, five cent coins. She was x-rayed and the decision was made to transfer Rebecca to a tertiary referral hospital in 500 km's away for surgery.

Jackie found this decision stressful as she is a single mother of six children, three children with disabilities. Jackie finds it difficult to find someone to look after her children when she has to go away. Her ex-partner was some support in this situation.

The flight was long and they did not arrive until early hours of the morning. Surgery was delayed twice, and with fasting times, Jackie was concerned with the amount of time that Rebecca had not had anything to eat. She was also concerned about the reasons for the transfer. If surgery could be delayed, then did she need to be transferred?

Jackie felt anxious and unsure. She felt that she had been left on her own and did not know her way around. She felt afraid to ask and was not shown around the hospital. Jackie did not want to leave her child and so relied on other mothers to help her.

Jackie did not know about Ronald McDonald House and she was not aware of any accommodations available to her. She was going to a parent's lounge to have cups of tea. It was not until she had been there two days that she felt able to speak up and ask a nurse where she could get something to eat. The nurse then told her the lay out of the hospital.

Jackie did not have any contact with the Aboriginal Hospital Liaison Officer (AHLO). On discharge she needed to find her own way home. She did not have any money. She did not know where to go to catch the train home, or if she would be able to do so. A nurse on the ward booked a car to take her and Rebecca to Broadmeadow train station. She was concerned that she would not be able to get a seat on the train, but this was not a problem and family arrived home safely.

Jackie's experience was very stressful for her and she did have several recommendations to offer. These included contact with the AHLO, staff to book travel for parents, handbook of what is available (accommodation, meals, teller machines) and an awareness from staff that it is not easy to travel to hospital with a child when there are children at home to look after.