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### Aboriginal People's Experiences of Health and Family Services in the Northern Territory

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#### Abstract

This paper presents the findings of a community-based participatory action research study that investigates Aboriginal people's experience of health and family services in the Northern Territory, Australia. The research is part of a larger program of work that addresses the multi-level change management required for implementation of the Northern Territory Government's Aboriginal Cultural Security Policy. Using empirical evidence generated from Aboriginal people—ranging across urban services through to remote locations—on the cultural security and cultural competence of current health service delivery in the Northern Territory, this article proposes a range of options for systemic, structural and individual level policy implementation and development of services.

#### Introduction and background

The research presented in this article represents the first of a four-stage process to implement the Northern Territory (NT) Department of Health and Families (DHF) Cultural Security Policy. Commencing in 2007, this policy work was designed to redress a reported lack of cultural security for Aboriginal people using government health services. The policy encapsulates a framework to develop and implement strategies ranging from cultural awareness, cultural safety to removal of systemic and structural barriers to services. The NT is one of the eight states and territories that comprise the federation of Australia. Health policy is developed and implemented at both levels of government, but is predominantly delivered at the state or territory administrative level.

Despite being a developed nation that frequently participates as a global citizen in the provision of support for developing nations, Australia's service provision performance in relation to its own Aboriginal people at all levels of government is poor (Australian Department of Foreign Affairs and Trade 2008). State, territory and federal administrations all have a record of chronic deficiency in delivering services to Aboriginal Australians (Department of Health and Community Services 2007b). Decades of public underfunding have amplified the consequences of a long-term inadequate response by institutions to provide services to Aboriginal people (Australian Medical Association 2007). The result is pervasive poverty among Aboriginal peoples and manifestly unequal health outcomes.

While Aboriginal people experience disadvantage, socially and economically, regardless of geographic location (Kennedy and Firman 2004; Walter 2008), those in the NT are even more likely to be living in hardship. Comprising 30 percent of the territory's population, more than half (58 percent) of NT Aboriginal people fall into the most disadvantaged quintile for socio-economic disadvantage (Australian Institute of Health and Welfare 2008). This economic poverty is reflected in current NT health statistics. Aboriginal Territorians are more than heavily over-represented amongst in-patients, making up 65 percent of those receiving such care; 85 percent of patients are around three times as likely to be receiving renal replacement therapy in this jurisdiction (Department of Health and Community Services 2007a; 2007b).

The causes of, and possible remedies for, the poor record of health service development and delivery for Aboriginal Territorians are complex issues. However, one identified factor is the limited knowledge or understanding of Aboriginal cultures and histories by those charged with health policy and service delivery (Sherwood et al. 2006). As an example, Maher (1999) indicates that the lack of this foundational knowledge may create misunderstandings, underpinned by different life experiences of health systems and knowledge and/or practise (Watson et al. 2002; Lowell et al. 2005; Fenwick and Stevens 2004; Wild and Anderson 2007). Trudgen (2000) and McConnel (2003) highlight the importance of cross-checking for understanding to ensure that ineffective communication does not impede effective health care service, even when the Indigenous patient speaks English (Devitt & McMasters 1998; Cheng et al. 2004; Belfrage 2007). In addition to considerations around histories, culture and language, Weeramanthri (1996) found that the communication process and information is critical in addressing the imbalance of power between the policy-makers, practitioners and community members, and the health system as a whole (Humphery et al. 2001). The purpose of this study is to create space for the Indigenous voice to express potential strategies for collaboration to improved services and engagement. As Kildea (1999) reported, the problem is not a lack of Aboriginal voice and call for change, but the 'willingness' to act.

An ongoing outcome of limited or poor understandings of Aboriginal people among service professionals has been the promulgation of culturally inappropriate constructions of Indigenous peoples and a failure to embed cultural security knowledge and skills within the health vocational curriculum (Sherwood et al. 2006). In recognition of this gap, the Australian Health Ministers' Advisory Council (AHMAC) recently endorsed the adoption of cultural security within service delivery. The accompanying national framework, *The Cultural Respect Framework for Aboriginal and Torres Strait Islander Health 2004–2009*, outlines standards for the development and implementation of cultural security plans. A central plank of these standards is that they must be developed in partnership with Aboriginal communities and to accommodate localised decision-making, accountability and setting of performance measures. Additionally, it is intended that the national framework be applied in synergy with other government policies addressing the health workforce and strategies to improve Indigenous health.

In 2008, the Australian Government also announced a 'Closing the Gap' campaign (Rudd 2009) to address disparities in health outcomes and other social disadvantages between Aboriginal and non-Aboriginal Australians. The NT government's response to this national policy direction is the Aboriginal Cultural Security Policy which was developed by the then Department of Health and Community Services (2007a). This policy begins by acknowledging the (Euro Anglo Australian) ethnocentrism embedded in current health service structures and systems. As the work of whiteness scholars such as Moreton-Robinson have demonstrated, it can be difficult for people from the dominant Australia culture to appreciate how their own cultural upbringing influences their interactions with people from other cultural realities. As a central remedial aim, the policy seeks to institute a new operating model that addresses intolerance, creates systems that support staff to work in a more culturally appropriate way, and removes service access barriers to embed Aboriginal cultural security into service delivery (Department of Health and Community Services 2007a). The achievement of this aim requires multi-level change management and the study reported here, a community based participatory action research study that investigated Aboriginal people's experience of health and family services, is one phase of a larger program of work to inform the successful implementation of the Aboriginal Cultural Security Policy.

As a final background note, in a somewhat ironical policy contradiction, this study on supporting cultural security was undertaken under the shadow of the Northern Territory Emergency Response (NTER) (Commissioner 2008) (commonly referred to as the Intervention) whereby Aboriginal people in the NT were subjected to new legislation, the *Northern Territory Emergency Response Act 2007*. This new Act introduced income management of social security benefits (quarantining of money), mandatory child health checks, along with removing the right to use the *Racial Discrimination Act 1975* (Cth), whilst the Commonwealth Government seized control of 60 Aboriginal communities across the NT. This policy has been referred to by many commentators as continuing colonisation through 'mainstreaming, assimilation or normalisation' (Altman 2009).

### **Cultural security**

Cultural security is a vital aspect of policies that impact on Indigenous peoples. As demonstrated in the literature (see Coory and Walsh 2005; Cunningham et al. 2005; Eckerman et al. 2006), along with sound competency measures, cultural security is integral to successful service delivery, policy formulation and reduction in discrimination incidents.

Cunningham et al. (2005) identified that clinicians and researchers alike need to be prepared to first understand how they might inadvertently contribute to the culturally unsafe environment and miscommunication problems and then to take steps to bridge the treatment and the evidence base gaps.

As elaborated in the work of Coffin (2007), the term 'cultural security' is defined in this project as the final stage in a continuum of development from cultural awareness, safety, and competency to security. Key principles for implementation of a cultural security policy include: changing service providers' behaviour; improving understanding of service providers' own cultural influences; actions at the structural, systemic and individual levels; ongoing organisational cultural competency evaluations that involve industry partners and Indigenous clients (Dunbar et al. 2009). Critically, this definition operates within the human rights agenda. It encompasses an active conceptualisation of cultural security, emphasising 'behaviour' over 'attitude' and 'action' over 'understandings' (Coffin 2007).

As noted above, the term cultural security is inclusive of the other cultural states on the cultural continuum: awareness, safety and competency. Cultural safety in this study is framed from an Indigenous perspective to mean opportunity to access and receive services without fear of discrimination, with cultural responsiveness from staff, in an environment that acknowledges and respects diverse cultural and language backgrounds. This definition, by default, incorporates an acknowledgment that those delivering services have a cultural awareness of the Aboriginal peoples with whom they are working and that their practice in working with and delivering services to those peoples displays cultural competence. An important accountability feature of cultural competence is reciprocity; that it is a two-way learning process between health service provider and consumer (Stewart 2006; Lowell et al 2005). Although objective evaluation of cultural competence is complex, the evidence indicates that it is an effective strategy for improving access and equity, cost-effectiveness and quality of health services (see Brach and Fraserirector 2000; Betancourt et al. 2003; Fortier and Bishop 2003). Brach and Fraserirector (2011) tested a conceptual framework for cultural competency based on patient reported measures of the physician's culturally competent communication behaviours. The framework included use of interpreter services, coordination with traditional healers and family members and immersion in the patient's culture. The study supported an association between positive patient satisfaction and trust of the physician and a decrease in blood pressure among the hypertensive patients. Another approach by Singer et al (2011) put forward a model the authors define as 'integrated patient care' where the patient is central and their care is coordinated and tracked according to their needs and preferences. Although the framework for measuring this type of care does not mention cultural competency, it does intrinsically monitor effective communication, involvement of the patient and their family in decision making in relation to care options and whether the care is aligned with personal views and beliefs about health care. Further research to test the various measurement frameworks for cultural competency is required to meet the policy imperative to address the slow progress revealed in national health outcome reports (Thomson 2005; Rudd 2009).

## **Study design**

The overarching aim of the study is to describe the health and family service experiences of a cross section of NT Aboriginal people, and to explore how these services might be delivered in a more culturally competent manner. This study focused on service delivery in the Health and Family Services sector, which is provided by the government, non-government and Aboriginal community controlled organisations.

### **Setting and location**

Nationally, Indigenous people comprise 2.5 percent of the total Australian population, but in the NT, 66,000 (31 percent) of the total population of 214,975 identify as Indigenous. This is highest percentage of Aboriginal people in any state or territory in Australia. Eighty-one percent of this population in the NT live in remote or very remote locations (Australian Bureau of Statistics 2006; 2008). Presenting service providers with unique challenges, there is also a high level of cultural diversity, with 65 living language groups (Gordon 2005). Health services to this highly dispersed population cover a landmass of 2,361,114 square kilometres. There is only one tertiary level hospital (with 363 beds) and supporting infrastructure is limited. Services are provided across five primary regions, each with a small hospital (the smallest has 20 beds) (Department of Health and Community Services 2008).

The NT Government provides 62 community health centres (54 in remote locations), which are complemented by 26 Aboriginal community controlled health services. Additionally, there is only limited, absent or poor quality information technology, transport services, housing and economic development, particularly in remote communities (Dunbar et al. 2009).

### **Partnership**

This study was established as a partnership between the Department of Health and Family Services, Aboriginal Medical Services Alliance of the NT and the principal researcher, based at the Charles Darwin University. The research partnership was inaugurated with the release of the Department's cultural security policy (Department of Health and Community Services 2007a), which provided the impetus for a supportive research agenda. This project involved Aboriginal community<sup>i</sup> engagement first and other issues such as workforce development, workplace reform, monitoring and accountability would be informed by the community engagement (Department of Health and Community Services 2007a).

The text box below describes each of these linked stages. As noted above, the research reported in this article relates to Stage 1 of this larger research program investigating Aboriginal community perspectives on cultural competence and cultural security in relation to service policy and delivery.

*Department of Health and Families Cultural Security Policy: Stages for implementation*

- Stage 1: Investigate Aboriginal community perspectives.
- Stage 2: a) Workshops to develop agreed model of change to improve cultural security.  
b) Develop cultural competency measures and outcomes.  
c) Obtain the baseline data against which implementation can be measured.
- Stage 3: An operational plan and strategy to market and communicate the new model prior to implementation in early 2010.
- Stage 4: Evaluation, against baseline data (Department of Health and Community Services 2007a).

Discussions between the research partners established the iterative cycles of progress reporting and enabling the Department of Health and Families to achieve outcomes through early implementation of critical strategies and to advise on the progress of the project. Members of this discussion group were all Aboriginal senior staff from members of the partnership organisations.

### **Research team**

The Aboriginal Medical Services Alliance of the Northern Territory and the Department of Health and Families were happy with the principal researcher's request to involve Aboriginal community groups and the employment of Aboriginal language and cultural researchers (hereafter described as co-researchers). The resultant field research team of 22 members included the principal researcher from Charles Darwin University, an Aboriginal researcher from the Aboriginal Medical Services Alliance of the NT (AMSANT) and 20 co-researchers. All researchers were Aboriginal people from the NT. The co-researchers provided one-on-one training on the process for research ethics, how to conduct a focus group session for research, and the reflection process following either focus groups or individual interviews. The principal researcher provided close mentoring support with training options for the co-researchers (including the development of facilitation tools such as conversation themes, note taking tools, questions to trigger reflection process and picture cards to trigger conversation) and with drafting the research report. The language of preference and cultural protocols to be followed within different regions across the NT were also established at this early stage, along with ethical protocols. An ethics application was approved by the Charles Darwin University Human Research Ethics Committee.<sup>ii</sup> The detailed research plan noted below was the basis for negotiation and agreement on approaches in each of the research sites. All co-researchers were remunerated using the NT Aboriginal Interpreter Service payment scales and acknowledged as consultant authors of the Stage 1 report in recognition of their contribution.

*Elements of the research plan*

1. Introduce the study to relevant organisations, gain advice and establish contact with local co-researchers;
2. Discuss group compositions and processes ensuring respect for culture;
3. Establish whether individual interviews or groups were preferred and what conversation prompts were acceptable. Make provision for flexible options for contribution by participants in person, telephone or written as preferred;
4. Establish the language of choice for interviews and focus group sessions and how this was to be provided (local or external interpreter);
5. Enquire whether the researchers should train co-researchers to run research sessions or whether the researcher could conduct these sessions with interpreters;
6. Establish the preferred location for interviews and groups and how these could be accommodated within budgets and timeframes; and
7. Investigate the most effective way for the research team and co-researchers to work together to reflect on the data and the research processes.

Five of the peak regional AMSANT member organisation Aboriginal boards agreed to participate in the study. These boards covered three of the five health regions within the NT. Members of these boards were representatives from across their regions. These board members contributed data along with contact details for suitable co-researchers to assist with further interviews. The remaining two regions were covered by two focus group sessions with the DHF Aboriginal health workers (AHW) networks, and the principal and AMSANT researchers (n=2) utilising their own cultural networks to identify further participants for the study, including Aboriginal elder groups.

***Recruitment and participation***

The participant population consisted of all Aboriginal people living in the NT with the exception of any person currently employed as a staff member within the health and family service sector. This exclusion was varied for data collection in the central Australian region where the majority of Aboriginal people do not speak English and early discussions identified the best way to collect data was through their community nominated DHF senior Aboriginal health workers. To supplement the data from the senior health worker, four focus groups were conducted in Alice Springs. This process, while different from that used in other parts of the NT provided reasonable coverage of Central Australia.

Participants were recruited into the study via a snowball sampling technique using direct invitations from AMSANT organisations and nominated co-researchers. Participation was voluntary. Across the five NT regional health zones, transparent and flexible approaches encouraged broad representation such as the co-researchers speaking discreetly in language to establish preparedness to participate. Researchers affirmed at the beginning of discussions that the intention was not to acquire sacred traditional knowledge but that if groups wanted to provide this information, cultural copyright acknowledgement would be noted. Aboriginal elder groups and Aboriginal boards of management associated with the AMSANT network advised that the information required by the researchers was appropriate and reasonable to share in order to improve services for Aboriginal clients.

In total, 47 focus group sessions (188 people) and 21 interviews were conducted with a total of 209 participants. By gender, 62 percent of these participants were female and 38 percent male. Research sites were broadly representative of the Aboriginal population across the NT, based on health regional zones and working through staff from both the Aboriginal community controlled health boards and the then Department of Health and Community Services' Aboriginal staff working across the five regional health zones.

### **Method**

Researchers worked with Aboriginal participants in their first language and data was gathered using a community-based participatory action research (PAR) framework, which was adapted to reflect Australian Aboriginal 'dadirri' principles and processes (discussed below).

Participatory action research as a research method has a double objective: to produce knowledge and action that is directly useful and to empower people at a deeper level through the process of constructing and using their own knowledge (Reason 1998, 71, cited in Walter 2010). As such, Walter (2010) has argued it is a research methodology as well as a method where the researcher is the tool to facilitate change, rather than the owner of the research project. It is the research subjects who determine what the problem or objective is and the change they want to achieve. It is also applied research. Rather than following a standard linear model, the research action of participatory action research is cyclic, following a process of planning, acting, observing, and reflecting and repeating these iterations until the desired outcome is achieved (Wadsworth 1998). The participatory, empowering and action outcome focus of participatory action research make it particularly amenable for use in Aboriginal community research. Its adoption provides the research infrastructure to allow the community to manage data collection, ascribe meaning and assist in identifying the outcomes of research (St Denis 1992). The combination of participatory action research practices with the principles and processes of *dadirri* further facilitate the cultural security underpinnings of this research project. *Dadirri* was developed by Aboriginal researcher Judy Atkinson (2001) and stipulates the principles and processes required to respectfully engage with Aboriginal communities. As defined by Atkinson (2001: np) these principles determine that the research must seek respect for:

- the knowledge and consideration of community and the diversity and unique nature that each individual brings to community;
- ways of relating and acting within community;
- a non-intrusive observation, or quietly aware watching;
- a deep listening and hearing with more than the ears;
- a reflective no-judgmental consideration of what is being seen and heard; and
- acting on learning's in a responsible way.

Within this methodological framework, rich data from in-depth conversations was produced using the qualitative methods of interviews, storytelling and focus groups.

### **Data collection**

Participative action research (PAR) cycles of planning, acting, observing and reflecting were used to collect data, identify and validate issues more broadly and identify solutions, with Aboriginal participants as both clients of services and practitioners. This process was recorded in detailed field notes, which were consolidated in a matrix presenting the summarised data and its analysis. The reflexive process between the co-researchers and the researchers were conducted after each regional visit. These sessions explored what themes were evolving from the data, important issues not raised, whether further people should be interviewed and what understandings emerged for professional research growth. These sessions provided insightful data and early recognition of emerging themes and, importantly, validated the research praxis undertaken in each region. The study valued Aboriginal languages and cultures in the research praxis, which were negotiated prior to conducting any research and under guidance from community selected co-researchers.

### **Data analysis and validation of information**

The primary aggregated data, which included the transcribed interviews and focus group sessions, was provided back to regional organisations for checking prior to reporting of the data in the study-monitoring group. This process allowed time for the regional organisations to consult more widely with community members and groups of Aboriginal Elders to ensure accuracy and provide additional input. A draft thematic report was provided to AMSANT for consideration and final clearance by its member organisations.

Data analysis occurred at several levels, initially through iterative group reflection cycles between researchers and co-researchers, and later between researchers, AMSANT and DHF. These meetings confirmed and refined themes. The use of an evolving matrix that arranged data thematically aided a third level of validation with Aboriginal Elders. The qualitative data software program ATLAS.ti (version 5.2.0) was used to organise the data and assist in its presentation and analysis.

### **Findings**

Aboriginal people were keen to share their experiences of health care and service delivery and the data collected and analysed proved rich in detail and understandings of the relevance of cultural security. The project's findings are synthesised within four themes and reflect a broad cross section of the field data: different worldviews; cultural knowledge and language divide; professional relationships: consumer, extended family and service provider; systemic failings.

#### **Different worldviews**

Despite wide acceptance that culture profoundly influences the way that people perceive and experience health and health problems, culturally unsafe services and barriers to services were reported by participants across the NT. Aboriginal participants consistently reported that the Department of Health and Community Services system and some staff members did not show respect for, or understand, Aboriginal views about life, and ways of living and being. Because the broader Aboriginal view of 'health' and 'family' are not embedded in policy and practice, health services are seen as unsafe environments and negatively affect mental and physical wellbeing. This can often cause anxiety, isolation and fear when individuals interact with the system.

There were many stories demonstrating cultural misunderstandings, sometimes with tragic outcomes for Aboriginal consumers. For example, an elderly Aboriginal man of high status in his community was admitted to hospital, at a time of bed shortages, and was placed in the maternal child health ward. This was a serious and disrespectful cultural breach. It not only caused the elderly man trauma, but also caused distress and social and emotional trauma to the Aboriginal women in the ward. One participant noted:

*... shame not just women it's a cultural thing sometimes it's not the right way and people would put rubbish on us. They will say we got no respect, we could get a flogging, there are real consequences for as Aboriginal people we have to be respectful and obey the rules.*

Another participant frequently reported situations related to renal patients' need to travel to towns for dialysis. Families commented that both the family and the patient worry if they are not together and in their own country. They reported that some people want to die on their own country and not in the hospital. It was stated that some sick people:

*... don't come or they run away. They don't live long these people, it's so sad if they only knew the situation maybe it could be done better. We know many stories; this is the first time anybody has asked us, Aboriginal people, what we think of these services.*

This sentiment was reported across urban and remote settings. Many research participants pointed to the evident lack of understanding on the part of service providers about the range of language and cultural differences in the NT. They felt this led to the adoption of generalisations, indifference to addressing cultural needs of consumers, and a sense of 'not caring' about what Aboriginal people perceived as being very important.

For example, when an Aboriginal patient does not have long to live, significant extended family members need to be involved in decision-making processes for the management of life support and/or palliative care. As one participant put it: *'... need to recognise time is not important but having the right people involved in the process is critical'*. It was reported that there is diversity regarding mourning practices for Aboriginal people and different cultural implications if the correct processes are not followed.

### **Cultural knowledge and language divide**

Participants described the potential for cultural shame and expressed real fear when health professionals are not aware of cultural protocols and how this should be articulated in the consulting environment. For example, health professionals who sit too close and make physical contact without explanation cause people to be fearful. This is amplified where there is also a gender difference between patient and health professional. One participant explained that *'these types of behaviours show no respect for the Aboriginal person or their family ... if it was me I would leave and not come back. This behaviour makes her shame, for females it is frightening with male doctors'*. In some regions, the issue of close physical contact was not identified as a major issue but it was acknowledged that this is a problem for some people, once again highlighting the diversity across the region.

Participants stated that when a person has experienced cultural shame, they might turn away and not look at the health professional, they might not respond verbally but use body language (such as nodding) and there might be times when the cultural breach is met with assertive talk.

*People are shame not just women ... it's a cultural thing sometimes it's not the right way and people would put rubbish on us. They will say we got no respect, we could get a flogging, there are real consequences for us as Aboriginal people we have to be respectful and obey the rules. This business about culture and not being respectful can go all the way back to our families we can get in trouble.*

Participants reported that there are issues when staff members lack cultural knowledge or make assumptions about the person based on previous experience from another region. It was stressed that staff members should be prepared to learn local protocols for the region where they are working. There are occasions when people get sick during cultural ceremonial activity and might need medical treatment. It is critical not to inadvertently breach regional knowledge. For example, it was explained by one participant that,

*December, January, February heavy rains, ceremonial commitments. There might be times when people get really sick during these times—not always time or appropriate to shower. Important that health professionals understand the strict obligations and cultural rules for people participating in these practices. Some of these issues relate to gender.*

Participants expressed language-based discomfort and tension due to not understanding signs and pamphlets and not knowing where to go, how long they will wait or the processes. This tension is transferred to the interaction between staff and patient. Often, when communication is already strained due to cultural or linguistic factors, participants explained there is no clarification process by staff. A tragic example of this was given in a focus group session about a relative's disappearance (presumed dead):

*A middle-aged man was told that he could go from hospital. What was not said is that you need to wait for the arranged transport and get your medications prior to discharge. This middle-aged man ... was still sick and when the doctor left the room he left and walked. This man did not reach his home and has not been seen since. His family went looking for him for a week after. He had kidney problems and this illness was explained by the doctor. It must have been a shock for him to be told how sick he was with no family around him.*

### **Professional relationships**

Unintended barriers arise where there is deference to the practitioners by Aboriginal people. This respect for practitioners was expressed by participants and reinforces the power imbalance in interactions.



One explained: *'They judge us and blame us for our sickness because we don't go to the doctors as much as white people, they would never think, that it is the difference in culture, and caring and understanding that can make a difference'*.

Participants repeatedly explained that they wanted to get to know the professional more, and for the professional to know them better. This story from one participant captures the experience reported in other participant stories:

*I took my wife to the doctor for the first time to have her baby. She was shame until she saw the old doctor that everyone knew ... It's the relationship that we need to form first; we are like anybody, we would like family doctors too.*

A participant who was frustrated by the need to always educate the new practitioner stated: *'I would just leave after giving them a talking to, they don't seem to listen, it's the same thing over and over. So, if it's in their training they have to listen'*. It is not just the literal interactions but also the unintended barriers and cultural breaches such as described by another participant:

*We do not feel respected when we have to wear gowns that do not cover us. It is cultural shame for young girls and women to see older men who are not covered and they are unable to help and move away so that they do not see this. It is not appropriate for us to wear things that are see-through. We ... feel shame and feel sorry for old people.*

### **Systemic failings**

Issues consistently raised were: the structural environments of the hospital and clinics; unfriendly staff in these health settings; problems with the application of the patient assisted travel scheme (PATS); the lack of regular delivery of family and allied health services; and almost total lack of continuity of care from providers (including language interpreters). Some participants considered they were not treated well based on observation and comparison of how others were treated. This made them feel sad and depressed but unable to do anything. One participant said that *'cultural awareness is a hit and miss affair. It gets worse after hours some Aboriginal people are turned away if they are not clean enough'*.

Participants described the mainstream system as *'not welcoming, sites of discrimination, and can be isolating ... sometimes we get very sad for our family. Our way is to have family around to look after us too'*. Participants reported many issues that do not seem to be taken into account when decisions are made about access to patient travel assistance. Some of the issues mentioned frequently centred on: the need to have family with the sick person; being able to involve family in the decision to nominate who should escort the sick person; the potential need to swap escorts where the length of stay interstate is lengthy; the use of public road transport at unsafe early hours of the morning for both pickup and drop off; absolute fear of air travel forcing travel by road at the patient's expense; and many Aboriginal families not having access to a vehicle or sufficient financial means to meet the costs of travel. In particular, Aboriginal participants acknowledged the inadequate application of the PATS<sup>iii</sup> guidelines:

*This 200km rule is stupid, Air Med drop off from Kilderk to Darwin but when they are returned home they are put on a bus and only dropped off at Timber Creek. They have no money and no lift to get home from there because they say that the person is within the 200km zone. This is a long way [a further 90 kilometres] to walk for a recovering sick person. It is outrageous.*

This participant's quote highlights how the objectives of a policy to assist patients gain safe access to service can have quite the opposite effect if it is developed without knowledge about the social, demographic, environmental and cultural contexts for Aboriginal patients.

### **Solutions: a better way to work together**

The purpose of this study was not just to document and analyse the experiences but also to use this data to develop a framework for how cultural security might be embedded into service policy and delivery. The collection of data about how the system might work better was recorded in table format against the emerging themes with columns identifying health care experiences, participant suggested solutions and synthesised researcher description of the solution. This document was a critical tool to enhance the regional organisations' capability to feedback to their communities and to validate and provide new data.

A general overview of the solutions are described below and arranged against where the change might occur—structurally, systemically or individually.

### **Structural changes**

A primary change raised by participants was for the Department of Health and Families senior executive to openly support and advocate for funded cultural security reform. Leadership at this level is crucial. Participants strongly advocated for coordinated regional level health and family service planning that captured monitoring of needs, progress and issues as determined by AMSANT, non-government agencies and government stakeholders. It was felt that this would provide greater coordination of service delivery and ownership of outcomes. Equally high on the agenda, was an increase in the level of Aboriginal people employed across the system and that the Indigenous cadetship program should be used for longer term recruitment of Aboriginal doctors, nurses and other health professionals. Additionally, there were calls for service buildings to have appropriate signage and the creation of a culturally safe environment.

### **Systemic changes**

Participants overwhelmingly requested professional development programs about Aboriginal cultural knowledge, with multi-level entry and exit points to suit the requirements of learners. Participants stressed that initial training should be regional and specific to work placement, developed and delivered locally to ensure currency and respect for the diversity across the NT. For example, participants referred to end of life decisions requiring significant others and family members responsible for the patient to be included in the decision process. As one participant said: *'The system and workers ... need to know more about us, to know how to relate to us, to make us feel safe, to make us feel that you want to help us. Not make us unsafe by breaching cultural protocols'*. Specific recommendations to emerge included:

- Cultural competence measures and assessment processes should be developed. Urgent staff development about the cultural competency standards, measures and assessment processes should be conducted. Cultural competence standards should form part of the essential criteria for recruitment and promotion of health professionals and managers.
- Participants also suggested that a culturally-friendly complaints system and policy and procedures developed to increase use of the Aboriginal Interpreter Services are critical to develop confidence to use the system. Participants reinforced the need for program administrators (such as PATS) to participate in cultural training, especially when arranging patient travel for expectant mothers.
- Poor English language proficiency, health literacy and different cultural constructs relating to medicines can (and do) lead to misunderstandings about dosage, side effects and safe storage protocols. There were calls for more care in explaining medicine dosage, storage and side affects with options where the person might not have access to a fridge.
- It was acknowledged that the sharing and referral of information, follow-up processes after appointments and monitoring of consumers in transit is well below the standard to keep consumers safe. Information linkage between the health and family service sectors for intra-Territory referrals requires review and establishment of standards for the system and individual staff members involved.
- Participants suggested that a review of the family and allied service delivery models, incorporating Aboriginal stakeholders, should occur to provide more culturally appropriate models. For example, there is need for protocols to address when not to travel on scheduled visits (ceremonial and funeral events).

### **Individual changes**

Participants commented that health and family professionals should reflect on practice and take note of the Aboriginal participant requests:

*... we need to develop trust and relationships with health and family health professionals, we need to feel that these professionals care for us as fellow human beings and respect our difference ... we think maybe they are not learning enough it needs to be more about our culture as a real thing not just something we follow. They need to understand this is our way of living in the world and provide services that respect our way.*

Equally, some study participants recognised the importance of learning more about the hospital system, family services and programs for their families and communities so that they can better access and lobby on behalf of family members. It was clear from participants that this should be communicated through relevant local languages and mediums.

### **Discussion**

The unsafe and distressingly poor experiences described by Aboriginal people are not new and have been identified through several decades of research (Carter 1987; Kildea 1999; Belfrage, 2007; Cheng et al. 2004).

The need for improvement to services at the structural and systemic levels, and how the institution supports staff to provide culturally secure quality health and family services, is critical in the NT. The complexity of reducing the life expectancy inequity for Aboriginal Australians is a shared responsibility. The cultural distance between service providers and Indigenous consumers is often extensive (Maher 1999; McConnel 2003; Trudgen 2000) and underlies the high risk of miscommunication, even for Indigenous clients fluent in English, when staff do not share the same cultural background and knowledge (Eckerman et al. 2006).

Staff power, miscommunication and lack of cultural knowledge have been identified as central to disparities of quality health and family service outcomes experienced by Aboriginal people (Cunningham 2005; Lowell et al. 2005). This observation triggers questions around why there has not been widespread reform before now. Since 2004, there has been unambiguous support at the national level through Health Ministers for the cultural respect framework. However, some commentators identified that unintended institutional discrimination does require significant political will at all levels to support investment of public time and resources, at the national, state and organisational levels (Pedersen 2005).

It is noted that the DHF has difficulty in attracting professionals to the NT (NT Department of Health and Families 2008). The desire to attract, acquire and retain professionals to work in the NT might have diverted the attention away from assessing against cultural competencies; such competencies are now considered essential. Additional challenges are emerging with workforce data showing a decreasing length of stay in remote areas and many fly in, fly out locums coming from interstate with minimal orientation. The process of becoming culturally competent in healthcare requires multi-level strategies and involves both 'top-down' and 'bottom-up' change management strategies. Reciprocal learning between health service providers and culturally and linguistically diverse consumers is also integral to fostering a culturally competent health system (National Health and Medical Research Council 2005).

In its public documentation, the DHF demonstrates a commitment to put into operation its cultural security policy through a process of embedding cultural competencies across all facets of its business. However, such commitment must not only take the form of unambiguous statements that 'good practice' is 'culturally competent practice' and 'quality health care' is 'culturally competent health care'; such statements must be backed with allocation of resources, and development of measures for cultural competence. Others contend that without the establishment of 'diversity champions' at the most senior levels, efforts at the individual level or in policy documents are unlikely to create or sustain substantial systemic change (Dowd et al. 2005).

### **Conclusion**

The NT cultural security policy implementation efforts made since 2007 have been a long journey over a short period of time. At the time of writing, in 2011, it is apparent that the DHF are trying to ensure that new recruits in the remote health workforce receive adequate training to understand how best to deliver services to people from a different cultural and linguistic background. Service outcomes since 2007 will require further investigation to understand the associated and direct impacts of cultural security policies and the implementation of strategies. Organisational change of this magnitude requires time and a level of momentum across DHF, AMSANT and the higher education sector. Such large-scale change management is not without its challenges. A serious challenge relates to maintaining synergy between the internal and external strategy implementation with the required development of cultural competency capabilities across the organisations. Change should also include participation by representatives from Aboriginal communities, as integral champions for the change and as the litmus test of what strategies are working.

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<sup>i</sup> The term 'Aboriginal community' is used flexibly and generally throughout the study to incorporate diversity. For instance, the term can be defined specifically in terms of a group of Aboriginal people with a common language, culture, religion and land or more generally in terms of a group/s of Aboriginal people forming a distinct segment of Australian society based on Aboriginal identity. It is not accurate to define an Aboriginal community based solely on geographical location. For example, within urban centres there might be many distinct Aboriginal language groups or 'communities' which can potentially come together as the 'Aboriginal community' voice for specific purposes.

<sup>ii</sup> Human Research Ethics Committee, Ref: H08031.

<sup>iii</sup> The Patient Assisted Travel Scheme (PATS) is what is applied to travel a patient to seek medical treatment but is not accessible for those patients who live within the 200km zone of the Health Centre.